FEASIBILITY OF THE FAMILY ACTIVITY ADAPTATION MODEL

IN IMPROVING BIMANUAL HAND USE IN CHILDREN

WITH HEMIPLEGIC CEREBRAL PALSY

by

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ABSTRACT

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Ellen Osei

Young children with HCP experience difficulties performing age-appropriate daily activities such as self-care and play. Research in neuroplasticity has shown that intensive, task-specific training in early development is ideal to maximize functioning in children with HCP. The aim of this study was to analyze the feasibility of a new manualized clinical guideline, Family Activity Adaptation Model (FAAM), via Telehealth to coach families to develop daily activities and routines that facilitate functional bimanual skills in young children with hemiplegic cerebral palsy (HCP). Ten caregivers and children with HCP (3-7 years) received virtual training on how to embed bimanual intensive training (HABIT) into their everyday activities and routines on their own at home for 90 minutes a day, 5 days a week over 8 weeks. Caregivers and children received virtual coaching using the FAAM method 2 times per week. FAAM Activity Analysis was used to describe manual development. Daily activity logs were used to assess family adherence and home program feasibility. Bimanual functional goal performance and satisfaction was measured using the Canadian Occupational Performance Measure (COPM). Perceived changes in overall bimanual functional skills

were evaluated using the Mini-Children's Hand Use Experience Questionnaire (Mini-CHEQ). Caregiver stress, burden and program satisfaction was monitored using the Parenting Stress Index (PSI-4-SF), the Ease of Caregiving for Children measure and a caregiver satisfaction survey. The measures were assessed immediately prior to (pretest), midpoint (burden measures only, repeated measures ANOVA) and immediately after (posttest, Wilcoxon Sign Rank Test) the intervention. All families made statistically and clinically significant improvements in goal performance ($p=.008$) satisfaction ($p=.007$), and overall bimanual hand use ($p=.035$). All families completed daily logs and practiced strategies for an average of 81.37 ($SD=7.069$) minutes a day. Caregiver burden and stress remained consistent throughout the study and all caregivers reported satisfaction with the program. This is the first study to manualize a family centered, telehealth-delivered intensive motor training program. This study adds a continuum of care and access to services for children and families with limited resources. The study supports clinicians with home program design and meets the individual needs of families using resources in their natural environment.

DEDICATION

Dedicated to the families and children with cerebral palsy and other special needs who participated in Raising H.O.P.E.'s outreach at the New Horizon Special School, Autism Awareness Care and Training Center, Haven International, and beyond in Ghana, West Africa. Thank you for inspiring me to embark on this journey as a researcher in effort to increase my impact and extend support to families worldwide. This is only the beginning!

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INTRODUCTION

Cerebral palsy (CP) is the most common childhood physical disability impacting approximately 1.5 to 4 in 1,000 births (Centers for Disease Control and Prevention [CDC], 2019). Cerebral palsy describes a group of non-progressive neurological disorders arising from prenatal or neonatal brain injury that primarily impact movement and coordination (Reddihough & Collins, 2003). Hemiplegic cerebral palsy (HCP) is characterized by motor impairments that are largely lateralized to one side of the body. Children with HCP experience deficits in movement and sensory processing, which result in significant difficulty with everyday tasks, especially with activities involving both sides of the body (Richards & Malouin, 2013). Difficult functional activities include self-care activities such as dressing, bathing, eating, and play activities (Fedrizzi, Pagliano, Andreucci, & Oleari, 2003; Pagliano et al., 2001). Difficulties with functional activities usually lead to "developmental non-use" of the affected extremity (Charles & Gordon, 2005; Taub, Uswatte, Mark, & Morris, 2006) and greatly impact their functional independence and quality of life. Primary caregivers of children with HCP are faced with responsibilities of seeking therapeutic interventions for the child, as well as supporting the child with self-care, school, and community-related activities (Alaee, Shahboulaghi, Khankeh, & Kermanshahi, 2015; Risdal & Singer, 2004;). Burden of care responsibilities are often linked to higher levels of stress, anxiety, and depression in caregivers (Parkes, Caravale, Marcelli, Franco, & Colver, 2011; Sawyer et al., 2011). In this context, the

process of motor learning and skill acquisition is closely related to the habits and lifestyle of children and their families.

Interventions that are commonly used to support children with HCP are Constraint-Induced Movement Therapy (CIMT) and Bimanual Intensive Therapy (BIT). These have focused on the movement and musculoskeletal needs of the affected body side. CIMT involves constraint of the less affected upper extremity combined with intensive unimanual training of the affected upper extremity (Taub, Uswatte, & Pidikiti, 1999). In a lab setting, play, fine-motor, and self-care activities are used to train the affected upper extremity while the child is wearing a cast, sling, or other constraint on the unaffected side for the entire duration of practice (Taub et al., 2004). The premise is that increased use of the affected side will promote learning of motor skills and better integration of the affected side in functional tasks. Evidence has supported the efficacy of this method, but the clinical implementation is difficult due to the restraining aspects of the method as well as the need to repeat training over time as development and complexity of tasks shift.

BIT involves intensive repetitive practice while using both the less affected and affected upper extremity without constraint. Hand-Arm Bimanual Intensive Training (HABIT) is a highly structured form of bimanual intensive training that uses specificity of training to support bimanual hand use in the context of goal-directed tasks. Elements of HABIT include whole task and part task practice, problem solving, increasing task complexity, and positive reinforcement in a play environment. Both CIMT and HABIT have been found to be effective in improving upper limb function in children with HCP; however, HABIT has been found to be more child-friendly and effective in improving

bimanual coordination and progress towards functional goals (An-Qin Dong, Hsi-Hsuan Tung, Wai-Yi Siu, & Nai-Kuen Fong, 2013; Brandao, Gordon, & Mancini, 2012; Fedrizzi et al., 2013; Novak et al., 2013; Sakzewski, Gordon, & Eliasson, 2014) and use in children with HCP (Brandao et al., 2012; Brandao et al., 2014; Charles & Gordon, 2006; Gordon, Schneider, Chinnan, & Charles, 2007; Ouyang et al., 2020; Ya-Ching et al., 2011).

Intensive motor-based interventions are not always accessible and feasible for families; as a result, home programs are often used by healthcare practitioners as a therapeutic strategy (Novak & Berry, 2014; Novak & Cusick, 2006). Occupational Therapy (OT) home programs using principles of Family Centered Practice (FCP) have also been found to be effective in improving upper limb function in children with HCP and have shown to be feasible for families (Novak, 2009; Novak et al., 2013). Novak, Cusick, and Lannin (2009) completed a randomized control trial analyzing the effectiveness of an Occupational Therapy Home Program (OTHP) in improving function and satisfaction with function and quality of upper limb skill in children with CP. The children were placed into three groups where they either received 4 weeks of an OTHP (n = 12), 8 weeks of OTHP (n = 12), or no OTHP where standard care was given (n = 12). The intervention followed a five-step process using principles of HCP that included (1) establishing a collaborative relationship between the practitioner and the caregiver; (2) setting mutually agreed-upon goals; (3) selecting therapeutic activities; (4) supporting parents through education and home visits; and (5) evaluating outcomes. Interventions in Step 3 were selected by the caregiver where they drew activities from a “library of ideas,” and were given the opportunity to determine how frequently and how long they practiced

the activities. The results reported statistically significant improvement across measures when compared to no OTHP with function and satisfaction with function, as well as quality of upper limb skills. While the OTHP approach has met the standards and expectations of families, there are no manualized guidelines for the family training or intervention strategies, making implementation difficult for practitioners to replicate (Novak, 2009; Novak & Cusick, 2006).

A study conducted by Morgan et al. (2016) brought together principles of FCP found to be effective in OTHPs, and motor learning-based intensive motor training in a home program for infants at high risk for CP. The study examined the impact of the protocol GAME (Goals, Activity, Motor Enrichment) and conducted a randomized control trial analyzing the effectiveness of GAME in improving motor skills in infants 3-6 months of age (n = 15), when compared to a control group receiving standard care (n = 15). The GAME intervention group received customized home program instructions that included goal-oriented intensive motor training, parent coaching, and environmental enrichment. The home programs were written along with goal-related illustrations, parenting strategies, ways to enrich the environment, and motor techniques for both independent and structured play time. Supervision visits were conducted once a week for between 60-90 minutes and varied as intervention progressed, according to the family's preferences and need to maintain fidelity of treatment. Specific motor interventions varied among families and were determined by the practitioner. Parents determined practice duration and frequency and tracked practice using daily logbooks. The results showed improvements in overall estimate of motor abilities and satisfaction with goal improvements. Parent mental health was monitored and was found to remain stable

throughout the course of the study. The results from this study showed that home programs designed to include principles of both family-centered practice and intensive motor learning may be beneficial and feasible for families of children with cerebral palsy. As this study was done exclusively with infants, little is known regarding how home programs of this nature may impact young school-aged children with CP. Specific impacts of this intervention on bimanual motor functioning are unknown; in addition, it is not known whether there are manualized guidelines for selecting specific motor learning techniques, dosing of intervention, and functional task selection while using this approach.

Efforts to translate evidence-based laboratory protocols (i.e., HABIT) in clinical practice have also been evident in the literature. Home-based intervention protocols are promising to develop conditions of task variability and intensity similar to laboratory ones. Ferre et al. (2017) conducted a randomized control trial examining the effectiveness of the HABIT when directed by the caregiver at home. The study included 12 caregivers and children assigned to receive the HABIT intervention, and 12 caregivers and children in a control group receiving lower limb functional training. The caregivers were trained over 5 days prior to the start of intervention and given a manual of instructions with educational materials and suggested play activities. The caregiver and child engaged in bimanual play and functional tasks for 2 hours a day, 5 days a week for 9 weeks (90 hours total), as outlined in the manual and prescribed by a supervising interventionist. Practice took place in a separate area of the home designated for therapy, and supervision was given remotely using Telehealth 1 time a week for 60 minutes. The results indicated improvements in functional goals and unimanual hand use; however, changes in

bimanual hand use were not seen. This result was in contrast to a previous feasibility home-based HABIT study, where the intervention included supervision of families 1 time per week in person and bimanual improvements were seen (Ferre, Brandao, Hung, Carmel, & Gordon, 2015). The study also reported an attrition rate of 25%, where caregivers thought the practice schedule was "too demanding." The results indicated that future studies considering HABIT in the home setting may benefit from additional caregiver support and distributed models of practice to create greater feasibility (Ferre et al., 2015; Ferre et al., 2017).

The home-based HABIT studies contain a structured and manualized approach for home program implementation using Telehealth; however, these studies follow a fully "prescribed" approach to intervention, whereby the toys and exercises to be used were assigned by the researchers and practice regimes of 2 hours had to be blocked out of the regular family day. On the other hand, the GAME study introduces a family-centered approach along with intensive motor training, but the therapist develops the program and strategies to be used based on the family resources and needs, but there is no training for caregivers and there is no manualized guide for therapist on how to develop the program.

The need to develop evidence-based, manualized home programs that engage the families actively in the therapeutic process, stems also from the increasing needs for accessing quality health care. Depending on geographical location, socioeconomic status, and availability, caregivers and children with CP may also experience a lack of access to supportive rehabilitation services and resources (Alaee et al., 2015; Novak et al., 2009; Resch et al., 2010). Telehealth is a form of patient care that uses visual and audio electronic communications to provide live services from one location to another

(American Telemedicine Association, 2020). Telehealth can be used to improve access to care and typically involves evaluation, monitoring, consultation, education, and training (Russell, 2009). A systematic review conducted by Camden et al. (2020) looked at the diversity of Telehealth practices for children with disabilities and the characteristics of treatment found to be the most effective. The review included 23 randomized control trials (RCTs) of children 0-12 years of age, with 14 of the studies including children with neurodevelopmental disabilities. The results found that interventions using coaching approaches via Telehealth for at least 8 weeks or more was most frequently correlated with improvements in functioning vs. solely providing information or feedback, and most studies reported high adherence and satisfaction with the intervention. The findings from this study support Telehealth as a means of improving support for families of children with cerebral palsy who may have limited access to care. The results provide greater insight into aspects of intervention that may be key in supporting families with making intensive motor programs feasible in the home setting.

Currently, there are no known interventions in the literature that inclusively meet feasibility standards for families, maintain the appropriate level of structured and skilled practice needed to improve functional goals, and are manualized to serve as a tool for therapists to use and examine systematically. The current researcher proposed use of the Family Activity Adaptation Model (FAAM). The FAAM is a manualized guideline designed to support caregivers in the implementation of intensive motor-based interventions in the home setting. The aim of the FAAM is to provide a guideline that clinicians may use to help caregivers gain awareness of how to incorporate intensive bimanual practice throughout their normal everyday activities and develop new “habits”

that support greater bimanual functioning. The purpose of this project was to examine whether the FAAM protocol in conjunction with the HABIT motor intervention can result in improvement in bimanual functional goals and support development of daily routines that promote skillful participation in children with HCP. Specifically, the study aimed to:

1. develop a manualized clinical guideline (Family Activity Adaptation Model-FAAM) to coach families to develop daily activities and routines that facilitate functional bimanual skills in young children with hemiplegic cerebral palsy (HCP);
2. examine the feasibility of implementing the FAAM in home settings using Telehealth;
    (a) examine the feasibility of training and supervision with caregivers and children;
    (b) assess family adherence to the guideline implementation requirements;
3. explore preliminary effectiveness of the FAAM to improve bimanual functional skills (patient-reported outcomes); and
4. examine caregiver burden and satisfaction with the FAAM Home program.

The FAAM intervention intends to support caregivers with adapting current habits and routines to support optimal functioning and quality of life for the child and the family as a whole. In the midst of the global COVID-19 pandemic and challenges of decreased access to services, the FAAM intervention introduces a client-centered practice that utilizes evidence-based therapeutic strategies and can be applied across different levels of client needs, across cultures and socioeconomic status. This is the first framework to

introduce self-directed goal-directed practice, using a manualized protocol that accounts for individual needs, preferences, and resources.

Chapter II

LITERATURE REVIEW

Children with HCP Motor and Functional Abilities and Limitations

Children with hemiplegic cerebral palsy (HCP) have suffered perinatal or postnatal brain injury, resulting in non-progressive delays in motor function that is largely present on the side of body contralateral to the brain injury (Gordon, Bleyenheuft, & Steenbergen, 2013). The types of brain injury include middle cerebral artery infarct, periventricular damage, hemi-brain degeneration, malformation of the brain, or post-hemorrhagic porencephaly (Ferre et al., 2020; Gordon et al., 2013). The result of brain injury leads to damage in the corticospinal tract (CST) and areas of the brain responsible for motor development. The brain injury type, timing, and location of damage to the CST result in impairments in manual dexterity, coordination, and reflex control (Gordon et al., 2013).

The gross motor abilities of children with HCP can be evaluated using the Gross Motor Function Classification System (GMFCS). The GMFCS is 5 level system used to evaluate the child's ability to sit, walk, and use of wheeled mobility devices. (Palisano et al., 1997) Distinctions between levels I-V are based on levels of support needed to navigate the environment. For instance, children with a GMFCS level I can walk and climb stairs without using support and may have decreased coordination, balance and speed. In contrast, a child with GMFCS level V displays impairment in all areas of motor function, and may be dependent on powered mobility (Palisano et al., 1997). The motor disorders associated with HCP are likely accompanied by difficulties with sensory

processing, epilepsy, cognition, behavior and communication challenges, and musculoskeletal problems. Musculoskeletal problems in HCP progress with the child's growth and include spasticity, dystonia, bone growth abnormalities, poor balance, and overall trunk and muscle weakness (Gormley, 2001). Spastic CP is the most common subtype (CDC, 2020). Spasticity is characterized by severe muscle stiffness that is caused by hypertonic muscles (Gormley, 2001). Dystonia involves sustained or intermittent involuntary muscle contractions (Quinby & Abraham, 2005). Muscle spasticity and dystonia may lead to contracture of muscles, difficulty with coordination of fine- and gross-motor functional movements, performance of daily activities (ex. Positioning, lying), and caregiving challenges (Gormley, 2001; Quinby & Abraham, 2005).

The manual functional abilities of children with HCP can be formally described using the Manual Ability Classification System (MACS). The MACS is a five-level classification tool used to evaluate how children with CP (ages 4-18 years old) use their hands to handle objects bimanually in their daily activities (Eliasson, 2008). In level 1, children have limited restrictions in task accuracy and speed and handle most objects easily and independently. In level 2, children may achieve certain challenging tasks with difficulty and handle most objects with a degree of reduced quality or speed. Level 3 includes difficulty with handling most objects and requires modification or adaptation of most activities for independent task completion. In level 4, children require continuous use of adaptive equipment for partial performance of easily managed objects or adapted activities. In level 5, the child is unable to handle objects and requires total assistance for task performance (Eliasson, 2008). The child's MACS level may also be impacted by their level of motivation and cognition regarding manual task completion (Steenbergen,

2006). A study by Demesi-Drljan et al. (2017) evaluated the functional abilities of children with CP in relation to CP subtype and associated conditions using the medical records of 206 children. Manual results were evaluated using the MACS and found that 88.9% of children with Spastic HCP were classified as either MACS level II (41.7%) or level III (47.2%).

Limitations in motor functioning observed in children who have HCP have been found to be also associated with greater non-motor challenges later in life essential to development (such as perception, executive functioning, and memory) (Forsman & Eliasson, 2016). Caregivers of children with CP may experience stress, as their role often includes supporting their child through the completion of their common daily activities (Eker & Tuzun, 2004; Halvarsson, Asplund, & Fjellman-Wiklund, 2010). The issue starts to become more prominent at the time when children transition to academic environments (preschools), where gradual independence in daily activities becomes an expectation. Between the ages of 3-7 years, children engage in daily occupations that include play, activities of daily living (ADL), and school-work (i.e., dressing, playing with toys, drawing and coloring, reading or looking at books, brushing teeth, eating, bathing, dressing, food preparation, pet care, dancing, outdoor play, and engagement in spiritual rituals or activities) (Chiarello et al., 2012; Dunst et al., 2001). Attention to bimanual skill development is of great importance in engagement with play, ADL, and school-related activities, as the less affected hand also requires training for optimal task performance and has been shown to underperform the dominant hand of typically developing peers (Rich et al., 2017).

Evidence-based Interventions

Recent literature has pointed to the need for evidence-based, intensive interventions to be included in routines of usual care, as motor-intensive interventions have been found to have a greater impact on upper limb functioning in comparison to standard care approaches alone with children who have CP (Sakzweski, Gordon, & Eliasson, 2014). Novak et al. (2020) conducted a systematic review evaluating the available evidence for interventions that help support and manage CP. The review selected articles published after 2012 alongside articles included in a 2013 systematic review (Novak et al., 2013) using the GRADE system for rating the quality of scientific evidence and the Evidence Alert Traffic Light System. The Evidence Alert Traffic Light System organized the evidence into three categories: “green” light indicates the highest quality of evidence available to use the approach, “yellow” light shows low or conflicting evidence and a need to measure outcomes carefully before use, and “red” light indicates sufficient evidence exists signaling the intervention as ineffective and should not be used. The search included 247 research articles on children with CP with any motor subtype, presentation, or motor ability classification level were graded by two independent raters who agreed unanimously. When it came to hand function interventions, bimanual training, Constraint Induced Movement Therapy (CIMT), environmental enrichment, goal-directed training, action observation, and home programs were given green light ratings. When looking at both hand function and self-care/overall functioning, goal-directed training and home programs were found to have the highest level of evidence.

Intensive Motor-based Therapies

Green-light intensive-motor interventions used to support children with HCP include Constraint Induced Movement Therapy (CIMT) and Bimanual Intensive Training (BIT). Extensive literature exists on the effectiveness of CIMT and BIT in improving upper limb functioning (Aarts et al., 2010 ; Brandao et al., 2012; Deppe et al., 2013; Facchin et al; 2011; Fedrizzi et al., 2012; Gordon et al., 2007; Gordon et al., 2011; Sakzewski et al., 2011).

The standard CIMT protocol with children takes place for 2 weeks and involves restraint of the more affected limb (restraint examples include a sling, splint, mitt, or glove) for 90% of waking hours and 6 hours of daily structured, repetitive intensive-motor training that includes shaping and massed practice (Morris, Taub, & Mark, 2006). The modified CIMT (mCIMT) is used to make practice less intense for children and incorporates greater use of functional activities (Cope et al., 2010). Protocols for mCIMT vary with restraint of the less-affected hand from 30 minutes to 6 hours of practice per day, 2-7 sessions per week, for 2-12 weeks (Kwakkel et al., 2015).

Optimal dosing for mCIMT needed to support child intervention acceptance and improve upper limb functioning in children with HCP has varied throughout the literature. The use of CIMT may also not be appropriate for all children with HCP. Cope et al. (2010) conducted a study analyzing the effectiveness of mCIMT in improving upper limb function, as well as brain reorganization pre- and post-intervention using functional magnetic resonance imaging (fMRI). Ten children between the ages of 7-14 years received mCIMT for 4 hours a day, 5 days a week over 2 weeks (40 hours total). Children in the group with greater spasticity and sensorimotor impairments (more than

50%) made small to no improvements in functioning, as measured by the Melbourne Assessment of Unilateral Upper Limb Function and kinematic analysis. The magnitude of fMRI signal in the primary motor area of the contralateral hemisphere was greater after mCIMT intervention for two children in the study. The results of this study highlighted the need for understanding the role that practice intensity and approach may play in brain reorganization and motor functioning after intensive interventions.

Yu, Kang, and Jung (2012) completed a randomized control trial evaluating the impact of a modified version of CIMT (mCIMT) on hand dexterity, grip strength, and ADLs in children with CP. Twenty children with HCP (mean age 9.4 years) were randomized to the mCIMT (n = 10) or a control group receiving standard therapy (n = 10). The control group received standard therapy semi-weekly for 30 minutes per session over 10 weeks. The mCIMT group received intervention for 60 minutes per day over 10 weeks. Grip strength was measured with use of a dynamometer, dexterity with the box and block test, and ADLs with a functional independence measure for children (WeeFIM). Statistically significant changes were seen from pre- to posttest across all measures. The results from this study further supported a need for modified versions of CIMT to support child-friendliness as well as improve upper limb function and functional skills. This finding was further supported by a previous study using a lower dosage (30 hours) of mCIMT with children who have HCP that combined the intervention with functional training of bimanual activities. The results revealed improvements in functional skills (Brandao et al., 2010).

BIT uses planned blocks of repetitive and direct practice of bimanual functional activities using both hands (Fedrizzi et al., 2012). Structured BIT has been found to

produce evidence for both improved upper limb functioning and functional skill development, regardless of corticospinal tract connectivity in children with HCP (Sakzewski et al., 2014; Smorenburg et al., 2017). A systematic review completed by Sakzewski et al. (2014) outlined existing evidence for effective upper limb therapy approaches for children with hemiplegic CP. The review included 24 RCTs with children ranging from 1-15 years of age, receiving either CIMT, mCIMT, mCIMT-BIT hybrid, or Hand-Arm Bimanual Intensive Training (HABIT) in comparison to each other or standard direct and indirect therapy (ex. physical therapy, occupational therapy, functional activity or goal-directed training, NDT, bandage wearing). Intervention activities took place in clinic, day camp, home, and community settings and were set up as intensive (1.5-6 hours of session time per day, 2-7 times per week, for 2-4 weeks with direct therapy for 18-126 hours and 21-240 hours of home practice) and distributed models of practice (1-3 times per week for 5-10 weeks, with 8-90 hours of direct therapy and 28-168 hours of home practice). Training activities involved regular therapy, repetitive task practice, shaping, whole and part task practice, reach, grasp, weight bearing, manipulation, fine motor, ADLs, functional training, play (structured and unstructured), and blocked and random practice. The review showed that both CIMT and bimanual task-oriented therapies produced stronger effectiveness in improving upper limb function, promoting neuroplasticity and achieving individual goals; however, bimanual therapy was able to address the limitations found in CIMT with coordination of the two hands and functional independence.

Practice intensity has been found to be the key ingredient and common factor in both CIMT and BIT and may lead to long-term impacts on functional hand use during

daily activities (Fedrizzi et al., 2013). A study by Fedrizzi et al. (2013) compared the impact of modified constraint induced movement therapy (mCIMT), Bimanual Training, and Standard Treatment in order to assess the long-term role of intensity of treatment in improving hand function and the persistence of the treatment effects 3 and 6 months after treatment in 105 children with hemiplegic CP. The study also evaluated the role of bimanual vs. unimanual activities in improving spontaneous use of the affected hand in play and ADLs. The children participated in a 10-week intervention for 3 hours a day, 7 days a week. The intervention was split into practice for 3 days a week at both a rehabilitation center with a therapist and at home with a caregiver (1.5 hours each), and the remaining 4 days a week solely at home where the caregiver would model intervention received at the rehabilitation center. The practice sessions included active problem solving with perceptual motor (ex. manipulating play dough), manipulative (ex. finger painting), posture and balance (ex. playing ball), self-care and other ADLs (ex. drinking from cup). A unimanual approach was used to complete each task in the mCIMT group and a bimanual approach in the BIT group. Outcomes were measured using the Quality of Upper Extremity Skills Test (QUEST) (evaluating dissociated movements, grasp, weight bearing, and protective extension) and the Besta Scales (evaluating grasp on request, spontaneous bimanual upper limb use during ADLs). The results indicated that the children in both mCIMT and BIT groups showed substantial improvements, while the control group receiving conventional therapy (40-60 mins of occupational or physiotherapy 1 time per week) demonstrated minimal to no change. The children in the BIT group showed gradual progress over time, and at 6 months both groups demonstrated increased spontaneous use of hand in play and life situations,

indicating that children learned new strategies for bimanual coordination in accomplishing developmentally appropriate tasks.

While both CIMT and BIT appear to have significant long-term effects on function, the literature has suggested that the use of BIT may be an optimal method of intervention with regard to child-friendliness, participation, functional goal-related outcomes, and overall bimanual coordination. An-Qin Dong et al. (2013) conducted a systematic review comparing the efficacy of CIMT and BIT in improving hemiplegic arm function and overall functional performance for children with unilateral CP. All studies included in the review included children with hemiplegic CP between the ages of 2-18 years. The intervention used in each study focused on the use of fine-motor play activities, circus training, upper limb games, and functional goal activities as a means of treatment with approaches that varied between structured and unstructured practice time. The practice time ranged between 3 to 6 hours a day, for 10-15 days in intensive day camps. Primary outcome measures included the Assisting Hand Assessment (AHA), the Canadian Occupational Performance Measure (COPM), the Jebsen Taylor Test of Hand Function (JTTHF), and the Melbourne Assessment of Unilateral Upper Limb Function (MUUL). The results showed that both training approaches produced similar effects in terms of the common outcome measures for children with unilateral CP. The study suggested that BIT may have a more significant impact on the daily activities of the child, as the model provides opportunities for direct practice of functional and meaningful goals and introduces opportunity for improved bimanual coordination and transfer of skills to unpracticed tasks.

Structured Bimanual Skill Training vs. Unstructured Bimanual Practice

While BIT has demonstrated a greater impact on bimanual coordination and functional goals in children with CP, there are limited structured approaches to the intervention available. Hand-Arm Bimanual Intensive Training (HABIT) is a structured, evidence-based approach to BIT developed to address the limitations presented with CIMT in improving bimanual coordination (Charles & Gordon, 2006). Gordon et al. (2007) conducted am RCT to evaluate the efficacy of HABIT in children with HCP. Twenty children (n = 10 HABIT group, n = 10 delayed control group) ages approximately 3-15 years received the intervention 5 days a week for 2 weeks (60 hours total). Specific upper extremity and bimanual coordination movement challenges were determined prior to the start of intervention. Practice took place in a child-friendly camp environment. Children were given the "rules" for play by the interventionist, and a list of age-appropriate fine- and gross-motor manipulation activities were then used to direct practice time. Bimanual activities targeting the bimanual motor challenge were selected for practice time. They key ingredients of HABIT practice included: non-restrained whole task (continuous practice for 15-20 minutes, not exceeding 1 hour) and part-task practice (practicing a targeted movement or shaping), where the more affected hand was used as a typical non-dominant hand (i.e., as a stabilizer, manipulator, active or passive assist), grading of task difficulty (i.e., modifying task speed or accuracy demands), positive reinforcement, and knowledge or performance. Children were given exercise programs to complete with a caregiver at home for 1 hour daily. Practice at home was logged by caregiver and continued for 2 hours a day up to 1 month after the intervention. The children were evaluated at pretest and posttest, and again 1 month after intervention

using the Assisting Hand Assessment (AHA), the Bruininks-Osertsky Test of Motor Proficiency (BOT), accelerometry, Caregiver Functional Use Survey (CFUS), the Jebsen-Taylor Test of Hand Function, and the kinematics of a drawer-opening task. Children in the HABIT group demonstrated improvements on the AHA and bimanual category of the BOT, increased use of the more affected limb as shown with the CFUS and accelerometry, and simultaneity of completing a drawer-opening task with two hands. The results of this study further showed that specificity in training is vital for improving bimanual hand use. The findings also indicated the importance of structuring the environment and activity choices in the absence of restraint use.

The structured skill practice found in HABIT has also been regarded as a key element in maximizing motor map plasticity (Friel et al., 2016). In an intensive bimanual training study by Brandao et al. (2014), 22 children (mean age of 8) were assigned to receive either structured or unstructured bimanual practice for 6 hours a day, 5 days a week for 3 weeks. Children in both groups used the same fine- and gross-motor play activities (ex. drawing, cutting, age-appropriate board games, playing with basketball), and children in the structured practice group received instruction that included repetition of isolated movements and progressed task difficulty and complexity. In the unstructured practice group, the interventionist did not structure or increase the complexity of tasks, but encouraged the children to keep the affected hand involved in play in a manner that was enjoyable for them. Both groups spent up to 30 minutes of practice time on functional goal training. The results were measured using the AHA for bimanual hand use, the JTTF for hand function, the ABILHAND-Kids and the Pediatric Evaluation of Disability Inventory (PEDI) for daily functioning, and the COPM for functional goals.

All groups showed improvement across measures; however, the group receiving structured training showed greater improvements on functional goals. As a follow-up, Friel et al. (2016) compared the effects of structured bimanual practice to unstructured practice with a focus on changes in motor map plasticity. Twenty children (mean age of 9), with the same dosage (6 hours a day, 5 days a week for 3 weeks) and similar criteria for practice (progression of task difficulty, repetition of isolated movements for structured group), were evaluated using the AHA, JTTHF, COPM, and Transcranial Magnetic Stimulation (TMS) to map representation of changes in the motor cortex. The results showed improvement across measures; however, children in the structured group showed greater improvements with functional goals and size of motor map changes up to 6 months postintervention.

Consistent with literature supporting BIT, HABIT gives an opportunity to approach intensive therapy for children with unilateral CP that allows for direct practice of bimanual skills and has little restriction or invasion and a greater regard for functional outcomes such as ADLs. Early HABIT studies (Gordon et al., 2007) have highlighted the importance of specificity of training in improving the frequency and quality of bimanual hand use, as 82% of all bimanual practice activities were spent on whole task practice of age-appropriate fine-motor and gross-motor activities. This study also found that providing the appropriate environmental structure and activity choices is essential for maintaining motivation and creating natural conditions during intervention. Brandao et al. (2012) compared children's functional skills and independence in self-care activities following unimanual CIMT and bimanual HABIT training. The researchers examined the interaction between magnitude of change and type of intervention, as well as caregivers'

perception of their child's functional goal achievement after administration of training in 16 children with hemiplegic CP. The children received intervention for a total of 90 hours (15 days, 6 hours a day) in a camp setting and were placed into two separate rooms (one designated for HABIT, the other for CIMT). A trained interventionist worked 1:1 with each child and selected activities according to each child's needs and progress. Examples of activities mentioned included play with fine-motor activities (ex. beads), board and card games, self-care activities (ex. eating), and gross-motor activities (ex. playing with ball), and were set up for either unimanual (CIMT group) or bimanual play (HABIT group). The activities were graded by modifying the complexity, speed, and accuracy parameters of the task, and all activities were completed with either a whole-task or part-task practice approach. Parents also completed 1 hour of practice at home daily with use of bimanual (HABIT Group) or unimanual (CIMT group) ADLs or play activities. While parents in both groups were equally satisfied, the HABIT group parents perceived superior improvements with functional goals, and there was a greater tendency toward improvement in self-care, functional skills, and caregiver assistance scores. The findings in this study draw attention to the importance of specificity of training in maximizing learning experiences and increasing daily functioning.

Specific parameters for practice dosage when using interventions such as CIMT and BIT have largely varied across the literature; however, recent studies have pointed to a more specific consensus for determining practice. Novak et al. (2020) completed a systematic review of randomized control trials to identify upper limb training approaches that yielded the greatest clinical gain, and the minimum dose of therapy for motor and individual goal improvement. Interventions included in the review were included if they

involved both active movement of the limb and whole-task or part-task practice of activities. Seventy-four RCTs were included with children aging from 0-18 years. Quantitative measures used in the studies included the AHA, the QUEST, the Melbourne Assessment 2, the Box and Block Test, ABILHAND-Kids, the COPM, the Goal Attainment Scale, the Pediatric Evaluation of Disability Inventory, and the Functional Independence Measure for Children. Aggregate data were used to summarize results for the AHA and the COPM. Interventions included were CIMT, BIT, and Hand-Arm Bimanual Intensive Training-Including Lower Extremity (in the Functional & Part-Task intervention category) and goal-directed training, Cognitive Orientation to Occupational Performance (CO-OP), and Goals Activity Motor Enrichment (GAME) (in the Top-Down Goal-Directed category). Results from a ROC curve analysis showed that a mean dose of approximately 57.4 hours was needed to see changes for functional interventions, and a mean range of approximately 14-25 hours for specific goal-directed intervention. The results demonstrated that interventions that are goal-directed and client-centered required a lower dose to produce clinically significant gains. The findings also showed that key ingredients of upper limb task-specific intervention usually involve: collaborative goal setting, whole-task and part-task practice, practice in natural environments, tasks with increasing complexity, feedback, motivation, and sufficient practice.

Taken together, consistent across the different frameworks proposed for improving motor skills in children with HCP, the common themes appear to be increased use of the affected side in goal-directed tasks, intensity of systematic practice, and specific movements in the context of these tasks to reveal the most successful outcomes.

Family Needs

In comparison to caregivers of typically developing children, caregivers of children with CP often face higher levels of stress and burden that lead to decreased quality of life for both the caregiver and the child (Carona et al., 2014; Ketelaar et al., 2008, Raina et al., 2005). Caregivers of children who receive "paramedical" or rehabilitative therapies share experiences that may produce additional factors of stress (Beckers, Smeets, & van der Burg, 2019). Intensive therapies that are delivered at home produce stress related to home program adherence and may lead the parents to make sacrifices that compromise their daily life and overall well-being (Peplow & Carpenter, 2013). Beckers et al. (2019) developed a framework to define and conceptualize parental stress in relation to therapy for caregivers of children with physical disabilities. The "therapy-related parental stress" model was developed based on focus group responses from mothers of children with CP. In this model, "Therapy" and intended or adverse effects were the central source of stress. The structure of "Therapy" was determined by parent, child, and family factors, the family-professional partnership, and the content and design of therapy. "Therapy-related parental stress" was represented by continuous phases of the perception and impact of therapy on subjective stress experiences, functioning and health, parental behavior, and development of the child. Subjective stress experiences were influenced by everyday living and caregiving demands. Functioning and health were influenced by the caregiver's coping resources. The stress produced from caregiver burden may lead to complete detachment from caregiver goals, stressing the importance of home programs using a collaborative family-centered practice model that

monitors caregiver levels of burden and stress as a target of intervention (Carona et al., 2014).

Ketelaar et al. (2008) conducted a cross-sectional study analyzing parents of children with CP and the relation between parental distress and child functional skill limitations and behavioral challenges. Forty-two families of children with CP ages 3-8 years old (60% with spastic HCP) were evaluated using the Pediatric Evaluation Disability Inventory (PEDI) (for child function), the Vineland Adaptive Behavior Scale (VABS) (to measure child behavior), and the Parenting Stress Index (PSI) (to examine emotional distress in relation to parenting). The results showed that the child's functional skills did not contribute to the parents' level of distress, but rather the child's maladaptive behavior in turn impacted the parents' sense of competence. This study further highlighted the importance of home-based therapeutic approaches that address the well-being of both the child and the caregiver. The constructs provided in "Therapy-related parental stress" provided an insight into understanding the specific psychosocial needs of the family when constructing home-based intensive therapies.

Home Programs for HCP

Home programs are used by many practitioners working with families of children with HCP as a means of continuing practice or carrying over intervention strategies to their natural environments, and introducing more opportunities for focus on specificity of training and functional goal training. Occupational therapy (OT) has been traditionally used to support children with HCP in performing their daily movement activities and routines in a way that increases their independence and enhances their quality of life. The work of OT often includes use of home programs with children who have HCP to apply

therapeutic strategies in the client's most natural environment, with activities that are similar to or directly represent the desired goal or task. Novak and Cusick (2006) completed a literature review to determine the key aspects needed to create OT home programs for children with CP. The review included an in-depth search of variables related to what is known about the effectiveness of OT home programs, evidence of intensity/dosage, and characteristics that encourage family participation. Of 28 articles found in the literature, 21 addressed and identified family preferences and characteristics of home programs that encourage family participation. The factors addressed included: a need for (1) interventions to have a family-centered functional approach, with activities incorporated into the daily tasks of the family to ease caregiver stress and promote increased child functioning; (2) provision of adequate caregiver education through documentation and illustration; (3) regular opportunities to evaluate caregiver competency and confidence through training in the learning style of the family; (4) home supervision that includes parent feedback and empowerment; and (5) regular evaluation of progress towards goals.

Principles of family-centered practice are commonly used by practitioners working with children who have HCP. However, to date, manualized guidelines for effective home-based intervention remain unclear. Novak et al. (2009) completed a RCT to evaluate the effectiveness of home-based OT home programs in supporting children with HCP to improve functional motor skills and parent satisfaction with functioning, as well as goal attainment, quality of upper extremity use, and level of participation. The intervention included implementation of the pilot-tested five-step clinical guideline for OT home program implementation (Novak & Cusick, 2006). The steps included:

(1) establishing a collaborative relationship with families, (2) setting mutually agreed-upon goals, (3) selecting therapeutic activities with family, (4) supporting program implementation through education and home visits, and (5) evaluating outcomes. The study included 36 school-age children (4-12 years old) divided into a 4-week intervention group (n = 12), 8-week intervention group (n = 12), and a control group (n = 12). In step 3, parents were directed to select activities from an educational resource provided by the interventionist ("library of ideas") that included structuring task practice (based on principles identified by therapist and parent knowledge of child), environmental adaptations, and parent education for each task. Each of these steps was used to develop an individualized home program for each family based on their particular goals using varying approaches such as goal-directed training, parent education, positive behavior support, play or recreation therapy, handwriting task therapy, adaptive equipment/ orthotics, CIMT, and strength training. Each parent determined intervention length and frequency of implementation throughout the study. The results found that the OTHP, when implemented at an average of 17.5 times per month for 16.5 minutes per session, produced significant changes in function, parent satisfaction with function, and quality of upper limb skill in school-age children with CP when conducted for 8 weeks. Parents were satisfied in terms of changes in child function and demonstrated adherence in terms of program continuity. The five-step process model has shown effectiveness in supporting families to improve upper limb function in children with HCP and applicability to other International Classification of Functioning (ICF) domains (Palisano et al., 2012). However, the study highlighted the greater need for this approach to be

developed into a clinical guideline and the overall critical need for OT home programs that may be used as a formal guideline.

The GAME (Goal-Activity-Motor Enrichment) protocol has emerged in recent literature as a promising intervention that brings together principles of the five-step process model for family-centered practice (Novak & Cusick, 2006) and intensive motor training in a home program for infants at high risk for CP. Morgan et al. (2016) conducted an RCT analyzing the effectiveness of the GAME in improving motor skills in infants 3-6 months of age (n = 15) when compared to a control group receiving standard care (n = 15). The GAME intervention group received customized home program instructions that included goal-oriented intensive-motor training, parent coaching, and environmental enrichment. The home programs were written along with goal-related illustrations, parenting strategies, ways to enrich the environment, and motor techniques for both independent and structured play time. Supervision visits were conducted once a week for between 60-90 minutes and varied as the intervention progressed, according to the family's preferences and needs to maintain fidelity of treatment. Specific motor interventions varied among families and included weight bearing, concentric and eccentric exercise, reaching and grasping activities, mCIMT, and BIT. Parents kept track of practice time using daily logbooks. Results from the Peabody Developmental Motor Scales-Second Edition (PDMS-2) and the COPM revealed improvements in the overall estimate of motor abilities (PDMS-2, Total Motor Quotient) and satisfaction with goal improvements (COPM) after 16 weeks and again at 12 months post-intervention. Parent mental health was monitored at baseline, 16 weeks, and 12 months post-intervention using the Depression, Anxiety, and Stress Scales (DASS-21) and were found to remain

stable throughout the course of the study. The results from this study showed that home programs designed to include principles of both family-centered practice and intensive motor learning may be beneficial and feasible for families of children with CP. This study adds to the literature on family-centered clinical guides for intensive home program design with children who have CP. As this study was exclusively done with infants, little is known about how home programs of this nature may impact young school-age children with a diagnosis of CP. Specific impacts of this intervention on bimanual motor functioning are unknown. It is also unclear whether there are manualized guidelines for selecting specific motor learning techniques, dosing of intervention, and functional task selection while using this approach.

The HABIT literature has illustrated an established clinical guideline for practice; however, few studies have illustrated a clear gold standard for home program development using this motor-learning based strategy. Ferre et al. (2016) conducted a study aimed to examine if children with HCP in a home-based HABIT program would make greater improvements in upper limb functioning, compared with a control group receiving an alternative lower limb therapy. Twenty-four children with HCP between the ages of 2.5 to 12.5 years were placed in either the intervention group (receiving the H-HABIT) or the control group (a functional lower limb intensive training group). Caregivers were given a total of 5 hours of training over the course of three sessions prior to the beginning of the intervention. The training session included 2 hours without the child present, where a review of procedures, reference materials, and demonstrations on how to incorporate and grade activities was given. The second session included another 2 hours of HABIT practice with the child present, where caregivers were able to practice

H-HABIT strategies and receive feedback on performance. The intervention began with the beginning of the third training session, where caregivers were supervised via Telehealth for 1 hour. Caregivers engaged in bimanual activities for 2 hours a day, 5 days a week over the course of 9 weeks (90 hours total). Caregivers were given a manual with education on HABIT techniques, reference of suggested functional and bimanual activities, and ways to increase the complexity of the task. The caregivers received remote supervision via Telehealth for 1 hour each week. Improvements at the end of the study were seen in dexterity as well as parent satisfaction with functioning; however, no improvements were shown in bimanual functioning in either the intervention or control group. The study also yielded a 25% attrition rate, with caregivers reporting the study schedule as "too demanding." This is in contrast with the results from the pilot home-based HABIT study, where weekly supervision was given in person and yielded improvements in bimanual functioning (Ferre et al., 2015). The results from this study bring attention to the need for structured family-centered guidelines within intensive caregiver-directed home interventions via Telehealth. Families who withdrew their participation from the study reported difficulty in meeting the demands of the study schedule in relation to their daily life. This contributes to ongoing questions of how the demands of intensive therapies can be structured to fit the individual characteristics and needs of each family.

Access to Care

Telehealth is a form of patient care that uses visual and audio electronic communications to provide live services from one location to another (American Telemedicine Association, 2020). Telehealth can be used to improve access to care and

typically involves evaluation, monitoring, consultation, education, and training (Russell, 2009). A systematic review conducted by Camden et al. (2020) looked at the diversity of Telehealth practices for children with disabilities and the characteristics of treatment found to be the most effective. The review included 23 RCTs of children 0-12 years old, with 14 of the studies including children with neurodevelopmental disabilities. The majority of interventions in the studies aimed to improve behavioral functioning (69.6%), with parents who were coached in implementing exercise programs through video conferencing (69.6%) at least 1 time per week, for 8 weeks or more. The results found that interventions using coaching approaches (Mean = 71%) via Telehealth for at least 8 weeks or more (87%) was most frequently correlated with improvements in functioning vs. solely providing information or feedback, and most studies reported high adherence and satisfaction with the intervention. The findings from this study supported Telehealth as a means of improving support for families of children with CP that may have limited access to care. The results provide greater insight into aspects of intervention that may be key in supporting families as they make intensive motor programs feasible in the home setting.

The current COVID-19 global pandemic has drawn further attention to the importance of intensive motor intervention protocols that are feasible and increase access to care for families. The restrictions posed by COVID-19 have created barriers to service access for individuals with movement disorders (Hassan et al., 2020). Children with CP require continued access to care, and the social distancing restrictions of the COVID-19 pandemic have presented large social, psychological, economic, and health burdens on children with CP and their families (Pazi, Adani, & Lamdan, 2020). Clinicians have also

experienced challenges with effective provision of care. A global survey on Telehealth use by practitioners across 40 countries between March and April 2020 reported a heightened increase in use of Telehealth, but lack of Telehealth training as one of many practitioner concerns at the beginning of the global pandemic (Hassan et al., 2020). The COVID-19 pandemic presents a critical need for structured guidelines that are beneficial to both clinicians looking to use Telehealth as a platform for intervention and families looking to benefit from continued care that maintains principles of family-centered practice during times of crisis and beyond.

The Family Activity Adaptation Model

A gap in literature currently exists within the context of home programs for children with HCP that effectively support bimanual hand use and are both replicable by practitioners and feasible for families to implement into their daily lives. Intensive bimanual training programs, specifically HABIT, have been shown to improve bimanual hand use when implemented in camp-based and lab-based settings (Bleyenheuft & Gordon, 2014; Brandao et al., 2012; Brandao et al., 2014; Gordon et al., 2007; Gordon et al., 2011; Green et al., 2013; Hung, Casertano, Hillman, & Gordon, 2011; Wahab & Hamed, 2015); however, the level of caregiver support needed for home program execution that may yield similar results remains unclear (Ferre, 2016). Literature has shown that home programs with a focus on family-centered practice are effective in empowering families, enhancing care feasibility and competency (Morgan et al., 2016; Novak, 2009; Novak & Cusick, 2006; Novak et al., 2007; Palisano et al., 2012; Rone-Adams, Stern, & Walker, 2004), yet there is a critical need for manualized protocols using this approach. The Family Activity Adaptation Model (FAAM) proposes to fill this

need by providing a manualized, clinical guideline for practitioners working with children who have HCP that includes key elements of effectiveness from both family-centered practice and BIT models of intervention. This researcher conducted a pilot study to investigate whether the conceptual framework of the FAAM would aid in the development of daily routines that support improvement in bimanual functional goals and home program feasibility. The pilot study results found that caregivers were able to accept and adhere to the FAAM Guideline, as well as maintain fidelity as measured by the use of FAAM Daily Activity Logs, a weekly Caregiver Activity Questionnaire, and a Final Caregiver Survey. The current study investigated the feasibility of the FAAM paired with bimanual intensive training (HABIT) delivered through Telehealth. The study aimed to develop daily routines that support home program feasibility, improve bimanual functional goals and overall bimanual functioning, examine caregiver burden, and support overall satisfaction with the home program. Home program feasibility was measured by FAAM Daily Activity Logs and caregiver attendance of training/coaching sessions. Bimanual functional goal achievement was measured by the COPM and overall bimanual functioning by the Mini Children's Hand Use Experience Questionnaire (Mini-CHEQ). Levels of caregiver burden was monitored using the Parenting Stress Index-4th Edition Short Form (PSI-4-SF) and the Ease of Caregiving for Children Measure. Overall satisfaction with the FAAM home program was measured through the FAAM Caregiver Satisfaction Survey. The FAAM presents an opportunity for home-based practice that is goal-directed and integrated into the family's everyday activities and routines. The FAAM protocol maintains important principles of family-centered care through the use of strategies that are customized to the individual resources available in the environment

of each family. The FAAM is manualized to increase access to care and support the replication of use with families and clinicians across different diverse settings.

Conceptual Framework

The FAAM Process Model

The FAAM is a service delivery model used to support practitioners in developing a family-centered approach to learning and practicing skills. The approach pairs the family's everyday activities and routines with intensive motor training protocols to maximize family (child and caregiver engagement) in the process of learning new motor skills. A train-the-trainer approach is used in the format of a virtual home program to guide caregivers through understanding BIT strategies, and introducing, changing, and shaping motor strategies with the child in a natural, playful manner throughout their day. The "FAAM Process Model" is used to guide practitioners in developing a personalized home program that aids the caregiver and child with development of new daily habits that support bimanual functioning. The FAAM "family" is identified as the child and the primary caregiver supporting the child through the selected activities in their natural environment. The FAAM is specifically designed for children between the ages of 3 to 7, within MACS levels I, II and III. The FAAM is based on the framework and literature of the International Classification of Functioning, Disability and Health, Child and Youth Version (ICF-CY) and OT, and further supported through evidence-based protocols within motor learning and adult learning literature. The FAAM Process Model is defined by three primary procedures: Family Orientation, Activity Analysis and Adaptation, and Model Motor Intervention.

Theoretical Underpinnings

The FAAM Process Model synthesizes principles of theoretical frameworks related to learning and considers the needs and expectations of the child and the family. Literature on participation in occupations of everyday life (Law, 2002) and the OPTIMAL Theory (Wulf & Lewthwaite, 2016) has emphasized the importance of providing choices that create the "just right challenge" for clients. For both caregivers and children, the focus is on active engagement and interactions with functional motor tasks in the context of meaningful activities that are relevant to their interests and lifestyles. The program incorporates the concepts of autonomy, enhanced expectancies, and external focus of attention (Wulf & Lewthwaite, 2016) as important principles to optimize motor learning. Autonomy refers to giving the children and caregivers choices not just about setting the goals, but also selecting the activities and objects to use (within the activity). The program allows the caregiver and the children to ask for feedback when they need it. Caregivers create priorities and choose what to bring up as concerns for them and the therapist to problem solve. Children are encouraged to take responsibility on the task and lead the activity.

Enhanced expectancies refer to providing positive feedback, altering perceived difficulty and definition of success, and changing conceptions of ability. The premise is that expectations can affect motivation and self-efficacy, and thus impact the person's ability to remain motivated and persist through a task even if it is challenging (Wulf & Lewthwaite, 2016). The FAAM program communicates basic characteristics that a task can have to support motor skill learning (i.e., shape of a handle to support functional grasp, or extending the time of a task to allow for more practice) and training on how to

provide positive feedback. Children and caregivers focus on the movement goal and not how the child's body moves. The emphasis is not on the task success or failure or even on the task difficulty, but on what the child (and the parent) can try and experience as well as possible strategies they can use to do a task (Dimitropoulou, 2019).

Caregivers are also given choices over the progression or regression of task difficulty and discuss with their therapist these choices to optimize learning in the family context. Caregivers are coached to provide positive feedback that focuses on the gains, on the exploration of new strategies, on an outcome that has been accomplished. Caregivers are trained to support children's perceptions about their abilities (not disabilities). Movement skills are framed as something that can be learned and changed, not as something "fixed." Caregivers and children are encouraged to focus more on learning; thus, while "failures" can happen, skills are still improving with persistent effort.

External focus of attention is key for the process of motor learning in the social context. This refers to the process of focusing not on the specific movements but on the movement effect (Wulf & Lewthwaite, 2016). Caregivers are trained to focus on the task rather than on how their child moves. They learn to use cues that shift their children's attention to external goals and encourage them to utilize new or better strategies. For example, they are given cues like "push the cart as hard as you can" rather than "use both hands to push the cart."

Taken together, these principles support motivation and encourage initiative for both caregivers and children. They also support the individuals' drive to persist independently with solving difficult problems and master challenging tasks in their environment.

The FAAM has also incorporated principles from theoretical frameworks of self-efficacy and adaptive decision making. Self-efficacy refers to a person's belief in his or her capacity to accomplish specific tasks (Bandura, 1997). It represents confidence in one's own ability to exert control over one's behavior, the outcomes of the behavior, and the social environment. In the context of learning motor skills, self-efficacy is reflected in self-controlled learning. Self-controlled learners are able to plan, self-monitor, and self-evaluate their learning at various points. The learning process is intrinsically motivated (Ryan & Deci, 2000; Zimmerman, 1994). Self-controlled learners select or create environments that optimize learning, such as seek out advice, experts, and information that support their learning process.

Adaptive decision making in motor learning supports the idea that motor skills are developing within the context of tasks and environments that support the learning process. Motor skills are "decisions" or "choices" that the person makes based on prior experiences, time and task constraints, and value/effort costs. In any given moment, infinite possible movements can be used to achieve the goal. Skilled performance relies on the person gathering and processing information and expanding the possibilities for action and the effectiveness of that action. Self-efficacy and confidence to persist in this process of exploration and discovery are key parameters to promote learning of new strategies and develop a flexible repertoire of motor strategies (Dimitropoulou, 2019).

In the FAAM process, caregivers and children are encouraged to develop their own activities and tasks. Emphasis is on them being in control of the learning process to select and create conditions, explore and develop strategies, seek advice, and create a flexible repertoire of strategies. The researcher anticipated that this will support the use of

these strategies in tasks more than those chosen to work on towards a goal, leading to changing (learning) motor skills, habits, and routines.

The Process of FAAM

1. Family Orientation:

   The family orientation process supports the practitioner with understanding the goals of the child and family, orienting to the family's daily activities and routines, and identifying the child's likes and interests. The information gathered during the family orientation is used to build rapport with the family and create an occupational profile. Occupations are life activities that are considered meaningful to the individual (American Occupational Therapy Association [AOTA], 2014).

   a. Goal development is guided by the COPM (Law et al., 1990) and focuses on self-care activities or participation in self-care routines where restrictions may be experienced due to limitations in bimanual functioning. The ICF-CY (2007) is used to guide the definitions of activity limitation and participation restriction for the FAAM. Activity limitation is defined as challenges that may be experienced by the child in executing (World Health Organization [WHO], 2007) bimanual tasks. Participation restriction is defined by difficulties the child may experience with completing (WHO, 2007) a bimanual self-care routine. The selected goal is categorized according to the most relevant occupational subdomain (AOTA, 2014). Occupational subdomains for children include ADLs, instrumental activities of daily living (IADLs), education, play, or social

participation. ADLs are daily activities that target self-care and may involve bathing, toileting, dressing, and feeding. IADLs in the context of the FAAM are more complex activities that support life in the home, such as pet care and religious and spiritual activities. The education and play subdomains focus on learning activities and activities, respectively, that are enjoyable for the child. The specific areas of focus for the FAAM include mealtime, playtime, and dressing activities and routines that are most important to both the child and the caregiver.

b. The practitioner collaborates with the caregiver and child to better understand the lifestyle and preferences of the family. This is referred to as the environmental and personal factors that impact activity and routine performance during the study. Personal factors considered with the FAAM include current habits, behavioral patterns, coping strategies, and practice experiences (WHO, 2007) in relation to bimanual tasks. The environmental factors are reviewed on an individual level (WHO, 2007) and focus on the materials in the home that may be available for bimanual practice, the set-up of rooms in the home, and the people who may be able to support with practice strategies. The caregiver provides a detailed account of the child's daily schedule and items that the child prefers during mealtime, playtime, and dressing. Emphasis is placed on the materials that are of interest to the child for increased motivation and provide a sense of autonomy during activity selection (Wulf & Lewthwaithe, 2016).

2. Activity Analysis and Adaptation:

The activity analysis is completed to provide the practitioner with a scope of how the child's personal and environmental factors may impact their ability to execute bimanual activities or participate in bimanual household routines. The specific personal factors taken into consideration for each bimanual goal are the family values, beliefs, and spirituality connected to the activity or routine, upper limb motor performance skills, and cognitive demands needed to support task completion (AOTA, 2014). Environmental factors are determined by assessing specific personal, physical, cultural, social, temporal, and virtual contexts that may support or challenge task performance (AOTA, 2014). The sequencing and timing of the task is then modified based on natural observation of the child performing each task and the goals for hand use.

The activity adaptation process supports practitioners in guiding the child and caregiver through activity practice and performance. To encourage motivation and attention while using the affected hand, the FAAM promotes engagement in normal daily activities, tasks that are identified as meaningful to the child and family, and social comparative feedback (Wulf & Lewthwaite, 2016). The specific FAAM strategies used to support motor learning in the social context include: increasing control over bimanual task conditions, providing choices for bimanual tasks, negotiating the structure of tasks, providing practice conditions that encourage task success and emphasize successful performance, and directing the individual's attention to the task goal vs. use of both hands. Creating opportunities where learning is

empowering for the child and guided by their goals and interests is imperative. Providing social support and feedback further enhances the process of learning. Social comparative feedback emphasizes the use of positive feedback (regardless of actual results) that suggests individual performance is more effective, or greater than normal or average, to enhance motor learning (Lewthwaite & Wulf, 2010). The FAAM protocol utilizes a real context-specific need that children and families identify and trains families to provide the comparative feedback support while the child engages in functional tasks.

3. Model Motor Intervention

   The motor intervention process of the FAAM includes use of coaching strategies to model intensive-motor techniques for the caregiver and child. The coaching strategies are guided by adult learning principles of engagement and evidence-based methods for coaching parents in the use of therapeutic strategies (Kaiser & Roberts, 2013). The coaching strategies are defined by three steps: Teach, Coach, and Review. These processes allow the practitioner to share specific modifications necessary for successful task performance with the family. The specific strategies are defined as: Teach—introduction of bimanual motor strategies to be learned; Coach—illustration of bimanual motor strategies taught, supporting child and caregiver engagement, monitoring progress); and Review (activity logging, providing new strategies for task success).

Incorporating HABIT into the FAAM Process

HABIT is used as the guiding principle for bimanual motor skill development

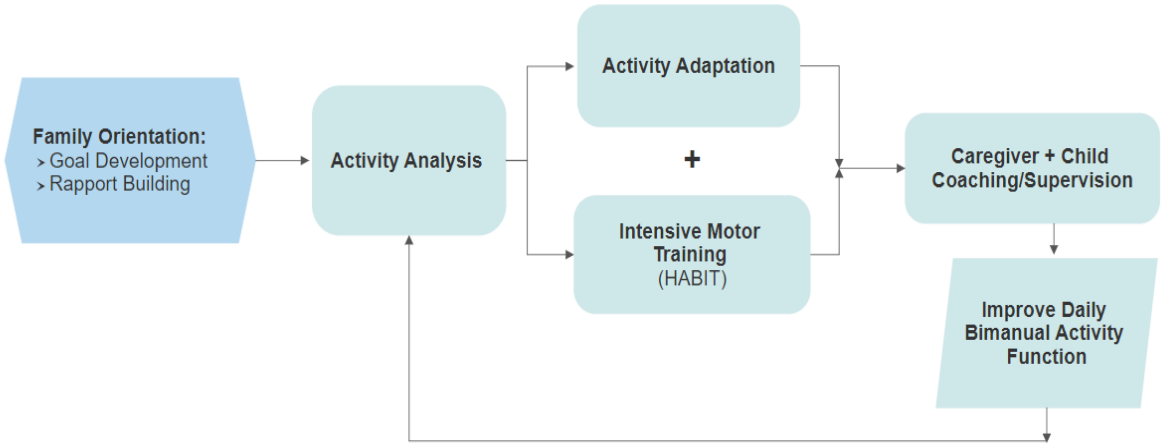
throughout the application of the FAAM home program. HABIT is an evidence-based bimanual therapy training protocol found within studies of motor learning. It creates opportunities for children and youth with hemiplegia to increase bimanual functioning through intensive practice that does not restrain the affected hand and uses child-friendly bimanual activities. The specific principles used in the FAAM focus on: practice intensity, whole-task practice, part-task practice, task grading, and functional goal training. Practice intensity has been found to be a key ingredient in promoting neuroplasticity (Gordon et al., 2007; Friel et al., 2016) and is promoted through provision of a consistent daily practice schedule for families, meeting a 60-hour minimum throughout the course of the program. Whole-task practice (practice of the task in a sequential and successive manner continuously for at least 15-20 minutes) is the primary focus for motor practice in the FAAM protocol, while part-task practice (practicing components of motor skills in smaller segments of time with increasing complexity and repetition) is encouraged as a secondary focus (ex. during task set-up or clean-up time). The FAAM approach to the HABIT application is used in an effort to remain consistent with the family's normal routine and modify activity approaches in a manner that allows for lifestyle adaptation within the family's timing.

Improve daily activity function and bimanual motor skills. The FAAM framework presents a manualized process for service delivery that aims to support development of motor skills in children with HCP in the context of everyday activities and routines. The FAAM model maintains recommended practice intensity for improvement in bimanual hand use and supports the interests, needs, and lifestyle of each family. The framework is guided by the ICF-CY and principles of occupational therapy,

motor learning, and adult learning literature. The FAAM combines meaningful occupations, contexts, client factors, motor performance skills, child engagement, motivation and autonomy, and structured caregiver coaching to support families through intensive home program use. The FAAM also uses strategies for family-centered support and key ingredients of bimanual intensive training, specifically HABIT, to produce a service delivery model for home programs that may be effective in improving skilled bimanual hand use within the context of the activity, those similar to the functional activity goal, and overall bimanual hand use. See Figure 1 for the FAAM process model.

Figure 1

The FAAM Process Model



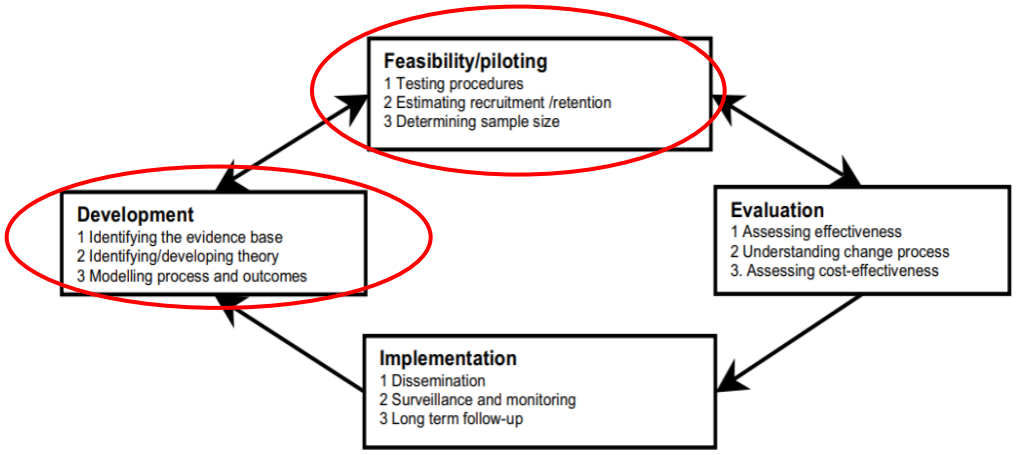
Chapter III

METHODS

To develop a manualized coaching and intervention protocol, the researcher followed the methodology suggested by the United Kingdom's Medical Research Council (MRC) for developing and testing complex therapeutic interventions (see Figure 2; Craig et al., 2008). The FAAM is a complex intervention because it meets the following specific criteria: a variability of outcomes, a high degree of flexibility or tailoring within the intervention, and a high number and difficulty of behaviors expected by those receiving or delivering the intervention (Craig et al., 2008). Based on this method, the development of the FAAM guideline is outlined in four non-linear phases: (1) development, (2) feasibility and pilot testing, (3) evaluation, and (4) implementation.

Figure 2

Developing and Evaluating Complex Interventions (Craig et al., 2008)



Phase 1 of the MRC framework involves identifying and reviewing existing evidence (see Appendix A, Pilot Study); developing theory (see Chapter II, Conceptual

Framework) that supports the new intervention; and modeling the intervention to understand the impact and areas that needed to be clarified. Phase 2 uses a mix of qualitative and quantitative methods to test the feasibility of the intervention and includes navigating through intervention acceptability, adherence, recruitment, and retention. This dissertation study was conducted to evaluate Phase 2 (feasibility) when conducted in the home using Telehealth, and to explore the preliminary effectiveness of the guideline to improve bimanual functional skills.

Purpose

The specific aims of the study were to:

1. develop a manualized clinical guideline (Family Activity Adaptation Model-FAAM) to coach families to develop daily activities and routines that facilitate functional bimanual skills in young children with hemiplegic cerebral palsy (HCP);
2. examine the feasibility of implementing the FAAM in home settings using Telehealth;
    (a) examine the feasibility of training and supervision with caregivers and children;
    (b) assess family adherence to the guideline implementation requirements;
3. explore preliminary effectiveness of the FAAM to improve bimanual functional skills (patient-reported outcomes); and
4. examine caregiver burden and satisfaction with the FAAM Home program.

It was hypothesized that the FAAM, when delivered using telehealth and paired with 90 hours of HABIT, would be a feasible and effective approach to facilitate

bimanual skills in children with HCP as they carry out daily routines. The HABIT protocol was used as an effective protocol to improve bimanual motor skills. The FAAM presents a new manualized guideline that was developed to guide clinical practice in home interventions for the HCP population. The FAAM also adds flexibility to the traditional delivery of HABIT (Gordon et al., 2007) to be implemented in home-based settings (Ferre, 2016) and delivery of services through Telehealth, and modifies the roles and responsibilities of both the practitioner and the caregiver.

Study Design

The study followed a mixed-methods, single-group, pretest/posttest design. The study took place for 8 weeks, where caregivers were coached through adapting their activities and incorporating HABIT techniques in their daily activities and routines using the FAAM approach. Baseline measurements were taken with the child and the caregiver prior to the beginning of intervention, and again 1-week post-intervention. Caregiver training took place for 1 day prior to the start of intervention and continued 2 days a week in the form of coaching/supervision throughout the length of the study. The child and the caregiver engaged in the intervention for 90 minutes a day, 5 days a week over the 8-week intervention period.

Participants

The participants for the study included children with HCP (n = 10) between the ages of 3-7 years with Manual Ability Classification System (MACS) of levels I-III and the caregiver or parent of each child participant (n = 10). The MACS categorizes the child's ability to manipulate objects used during daily activities and is described by five

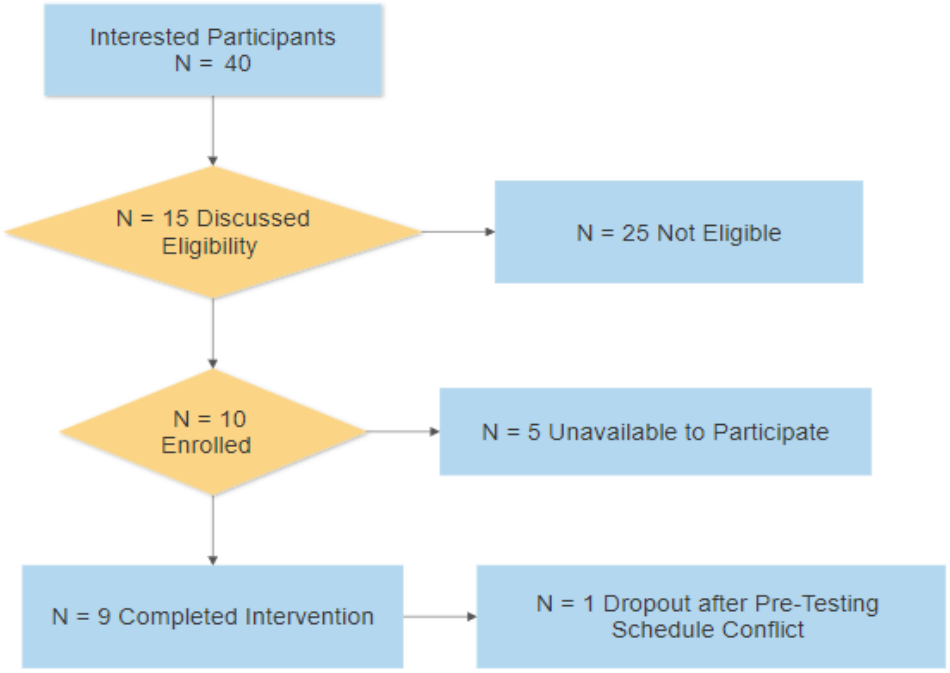
levels of functioning (Eliasson, Forssberg, Hung, & Gordon, 2006). The MACS literature has shown that the tool demonstrates high construct validity and interrater reliability with an intraclass correlation coefficient of 0.97 (Eliasson et al., 2006). The participants were also classified according to the Gross-Motor Function Classification System (GMFCS). The GMFCS (Palisano et al., 1997) categorizes the child's ability to complete movements independently in relation to sitting and walking across five levels. The GMFCS literature has shown both construct validity (Palisano et al., 2000) and interrater reliability (Bodkin, Rosenberg, & Perales, 2003; Galuppi & Rosenbaum, 2004).

Recruitment

Caregivers and children were recruited via electronic flyer through the Children's Hemiplegia and Stroke Association (CHASA) as well as through word of mouth by individuals who provide resources to families of children with cerebral palsy (Center for Cerebral Palsy Research, Teachers College, Columbia University). Purposive and convenience sampling was used to select families who met age, presentation (HCP), and location criteria (within the United States). See Figure 3 for FAAM participant enrollment.

Figure 3

FAAM Participant Enrollment



Inclusion/Exclusion Criteria

The inclusion/exclusion criteria were based on previous HABIT studies (Ferre, 2016; Gordon et al., 2007). Child inclusion criteria included: (1) the ability to grasp and release with the affected hand, and (2) the ability to follow two-step directions. The inclusion criteria for caregivers included that they were the adult who typically carries out the selected routines with the child. The caregiver and the child completed screening via video call to confirm the child's condition and level of functioning. Exclusion criteria included: (1) an inability to grasp or use the affected hand as a stabilizer, (2) health diagnoses that were not associated with cerebral palsy, (3) cognitive delays that would prevent the child from following one-step directions, and (4) visual problems that may prevent completion of intervention tasks or testing. Exclusion criteria for caregivers was

an inability to participate for the entire length of the intervention. See Tables 1 and 2 for child and caregiver characteristics, respectively.

Table 1

Child Characteristics

Participant #	Age (yr.)	Gender	Ethnicity/Race	Functional Impairment	MACS	GMFCS	Mini CHEQ: Baseline Overall Hand Use (1= Not Used, 4=Good)
(1)	5	Male	Asian	Right HCP	II	I	--
2	4	Male	White	Left HCP	II	I	2.2
3	6	Female	White	Left HCP	II	I	1.1
4	4	Male	White	Right HCP	II	I	2.2
5	6	Male	White/Hispanic	Left HCP	III	I	1.2
6	7	Male	White/Asian	Left HCP	II	I	2.4
7	5	Male	Asian	Right HCP	II	I	1.9
8	6	Female	South Asian	Left HCP	III	I	1.5
9	3	Male	White	Left HCP	II	I	1.8
10	6	Male	White	Left HCP	III	I	1.1

Table 2

Caregiver Characteristics

Participant #	Age	Gender	Race/ Ethnicity	Language	Education	Marital Status	Income (annual)	Location
(1)	---	Female	Asian	English	---	Married	---	Massachusetts
2	34	Female	White	English	4 Yr Degree	Married	10,000-30,000	Florida
3	38	Female	White	English	Doctorate	Married	110,000+	Utah
4	39	Female	White	English/Russian	Professional Degree	Married	---	Hawaii
5	37	Female	Hispanic	English	Some College	Married	110,000+	New York
6	38	Female	Asian	English	Professional Degree	Married	---	California
7	37	Female	Asian	English	Professional Degree	Married	----	Illinois
8	42	Female	South Asian	English	Professional Degree	Married	110,000+	New York
9	35	Female	White	English	Doctorate	Married	110,000+	New York
10	39	Female	White	English	Professional Degree	Married	30,000-50,000	Oregon

Outcome Measures

The quantitative measures for the study were the Canadian Occupational Performance Measure (COPM), the Mini Children's Hand Use Experience Questionnaire (Mini-CHEQ), the Parenting Stress Index (PSI), the Ease of Caregiving Scale, FAAM Daily Activity Logs, and FAAM Training/Supervision Attendance. The qualitative measures were the FAAM Activity Analysis and the FAAM Caregiver Satisfaction Survey. Table 3 outlines the use of these measurement tools according to the research questions, the specific variables that were measured, and the procedure for measurement.

Table 3

Measures Used According to Research Questions, Variables, and Procedure

Research Question	Variable(s)	Measures Used	Procedure
(1) Develop a manualized clinical guideline (FAAM)	Pilot Study outcomes (Design/Process Feasibility) Guideline development	- Pilot Study Daily Activity Logs, COPM, & Caregiver Satisfaction Survey - FAAM Activity Analysis	- In-person Testing - Practitioner review of caregiver & child video
(2) Examine the feasibility of implementing the FAAM in home settings using Telehealth	Adherence to Guideline	- Daily Activity Logs - Coaching Session Attendance	- Caregiver Online Survey
(3) Explore preliminary effectiveness of the FAAM to improve bimanual functional skills (patient reported outcomes)	Bimanual Functional Skills Bimanual Functional Goals	- Mini-CHEQ - COPM	- Caregiver submitted document independently - Caregiver & Practitioner develop collaboratively
(4) Examine caregiver burden and overall satisfaction with the FAAM home program	Level of Caregiver Burden Caregiver Satisfaction	- Ease of Caregiving Scale - Parenting Stress Index - Caregiver Satisfaction Survey	- Caregiver submitted document independently

The first purpose of this study was to develop a manualized clinical guideline (FAAM) (see Appendix B) to coach families to develop daily activities and routines that facilitate functional bimanual skills in young children with HCP. The measurements from the pilot study included FAAM Daily Activity Logs, the COPM, and the FAAM Caregiver Satisfaction Survey. The FAAM Daily Activity Logs were used to examine the caregiver's ability to use the tool consistently and effectively; the COPM was used to evaluate bimanual goal performance and satisfaction with performance, as reported by the caregiver; and the FAAM Caregiver Satisfaction Survey was used to analyze the caregiver's overall satisfaction with the program and gather feedback for study design improvement. This outcome was measured during the pilot study to test the feasibility of the intervention process and design and to develop the foundation for the FAAM Guideline. The measure from the current study was the FAAM Activity Analysis (Appendix C) , which was used to create a profile of the child's bimanual functional goals as reported on the COPM, and the specific factors that impacted the child's task performance. The factors included: understanding the values and beliefs associated with the goal, personal, social, physical, and temporal contexts that may support or challenge task performance; social demands associated with task performance; objects required; activity sequencing; and major manual muscle movements required for performance.

The next aim of the study was to examine the feasibility of implementing the FAAM in home settings using Telehealth. To examine the feasibility of the weekly training and supervision sessions with the caregiver and child, the researcher kept a log of weekly attendance. Additionally, the researcher used the FAAM Daily Activity logs (see Appendix D) to assess both feasibility of training and the family's adherence to the

guideline implementation requirements. The FAAM Daily Activity Logs contained both quantitative and qualitative measurements; they were designed specifically for the FAAM to track the amount of time spent completing each task daily. The logs contained space for the caregiver to write the type of task performed; the time of day (morning, afternoon or evening); how many minutes it took to complete each task; whether the task difficulty was increased or decreased; and total time spent performing activities (out of a target of 90 minutes). A brief questionnaire was provided at the end of the log to ask the caregivers to rate on a scale of 1-5 their ability to fit activities into their daily schedule, how well the child tolerated the activity changes, and their ease with consistent strategy use.

Then, to explore the preliminary effectiveness of the FAAM to improve bimanual functional skills (as reported by the caregiver), the researcher used the COPM and the Mini-CHEQ.

The COPM (see Appendix E) is an evidence-based outcome assessment tool used to quantify change in a client's perceived performance and satisfaction with the performance of occupation-based tasks over time (Law et al., 1998). The COPM was used to measure changes in perceived bimanual functional goal performance as well as satisfaction with goal performance from pretest to posttest. First, the caregivers were asked to identify daily activities or routines that were meaningful to them and with which they wanted to see improvement. Then, the caregivers were asked to rate the importance of each activity on a scale of 1-10. Based on their ratings, caregivers selected three of the most important goals for intervention and rated their child's performance and satisfaction with the performance on a scale of 1-10. The COPM has been found to be a valid and

reliable measure that effectively captures changes in occupational performance and is foundational in the development of strong intervention strategies (Carswell et al., 2004). Clinically significant change on the COPM is determined by a change in a score of three points or more. This measurement is consistent with previous home-based upper limb studies for children with HCP where caregivers served as the primary interventionist (Ferre, 2015; Novak et al., 2009).

The CHEQ is a subjective survey developed for children with HCP that measures the child's experience engaging in a variety of everyday bimanual tasks using their affected hand from the caregiver's perspective. The mini-CHEQ (see Appendix F) was used to measure the parent's perception of the child's experience with overall bimanual hand use during tasks prior to and post-intervention. The Mini-CHEQ was designed for children ages 3-8 years old and contains items and questions that are age-appropriate for the population in this study. The Mini-CHEQ contains 21 questions about bimanual activities given in random order. When filling out the survey, parents were asked to answer if the activity was typically performed independently, and if one hand or two hands were typically used to complete the task. Each question included three sub questions rated on a scale of 1-4 on the child's hand use, time taken to complete the task in comparison to their peers, and how "bothered" they may feel while completing the activity. Although the Mini-CHEQ is a new untested version of the CHEQ, the CHEQ was developed using Rasch analysis and has been found to be a valid and reliable tool (Amer et al., 2015; Skold et al., 2011).

Finally, to examine caregiver burden and overall satisfaction with the FAAM home program, the researcher used the Parenting Stress Index, the Ease of Caregiving for Children, and the FAAM Caregiver Satisfaction Survey.

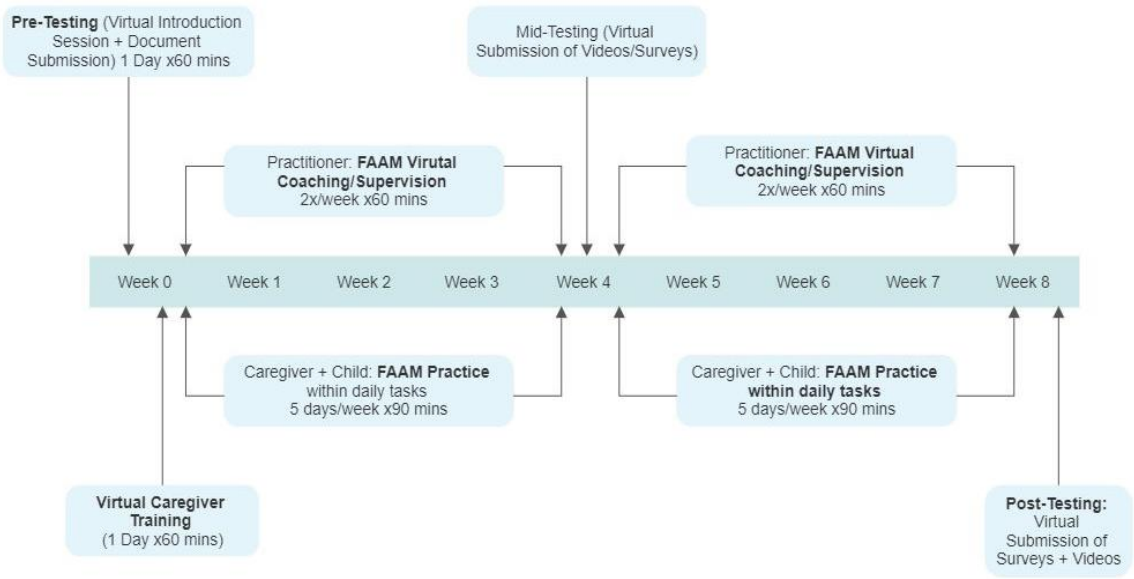
The Parenting Stress Index-4th Edition Short Form (PSI-4-SF) (see Appendix G) is a screening tool that looks at the levels of stress within the parent-child system and identifies concerns that may lead to issues with parent or child behavior (Abidin, 2012). The tool contains 36 items rated on a scale of 1-5 (strongly agree to strongly disagree) and is administered through caregiver report. The PSI-4-SF domain assessment includes Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), Difficult Child (DC), and Total Stress (TS). PD describes the degree of stress the caregiver may experience in relation to personal factors and parenting. P-CDI identifies the dynamics between the caregiver and the child and the parent's perception of the child as a negative aspect of their life. DC reviews stress in relation to the behavioral aspects of the child that may make parenting easy or difficult. TS refers to the overall level of parenting stress with the combined domain scores. The PSI-4-SF has been found in the literature as both reliable and valid, and clinically significant percentile scores are ≥ 85.

The Ease of Caregiving for Children (see Appendix H) is a scale that looks at the levels of difficulty experienced while safely supporting a child with completing various ADLs. The scale is a 12-item parent-report Likert scale measurement on a scale of 1 to 5, where 1 = very difficult and 5 = no help is needed. Evaluation factors considered for each item include level of safety while performing the task, the physical demands on the caregiver, the caregiver's confidence about helping the child, and the time needed to complete each activity (Ward et al., 2014). The scale has been found to have both test-

retest reliability (ICC = 0.69) and construct validity for children with cerebral palsy 1.5-11 years (Alghamdi et al., 2020). The FAAM Caregiver Satisfaction Survey (See Appendix I) was developed as an open-response form to provide caregivers with the opportunity to provide details about their personal experiences with the home program. The survey contains six items exploring the ease of adapting FAAM strategies to their daily routine, average practice time per day, family centeredness and support, and they would recommend the program to others. Figure 4 depicts the measures used during the 8-week conduct of the study.

Figure 4

Measures Used During the 8-week Study



Procedures

Pretesting and Caregiver Virtual Training

Week 0. During the first day of training, the caregiver and child completed the FAAM orientation. The caregiver and child received consent and assent forms,

completed demographic information (see Appendix J) and the practitioner reviewed educational material regarding the FAAM home program with the caregiver. The practitioner and the caregiver completed the COPM to establish bimanual goals for the study and the CHEQ questionnaire to establish baseline perception of the child's experience with bimanual activities. To complete the FAAM Activity Analysis, the caregiver verbally expressed the values and beliefs associated with each goal, contextual supports and challenges experienced, and objects available to complete each task associated with each goal. The social demands, activity sequencing, and muscle movement required for each goal were analyzed through three 3-5 minute video clips recorded and submitted by the caregiver at three separate time points during the week (see Appendix K) The practitioner then analyzed the information viewed in the video and used it to inform methods for adapting the activity during the intervention phase, as outlined in the FAAM Guideline Manual (see Appendix B). A brief version of this data form was used as a tool to guide and modify intervention strategies over the course of the study. The specific evaluation factors included motor engagement of hands, duration of activity, needs for parent intervention, and task completion.

Following pretesting procedures, training in the FAAM techniques took place virtually for 1 day over the course of 60 minutes in the home of each family and included both the child and caregiver. During the training session, the practitioner shared strategies for adapting the task according to the findings from the activity analysis, and ways in which the strategies could be applied across different daily activities during their day.

FAAM Coaching and Intervention Protocol

Weeks 1-8. The FAAM coaching and intervention took place over the course of 8 weeks. FAAM coaching took place 2 times per week for 60 minutes, totaling 16 hours of coaching. FAAM intervention took place 5 days a week for 90 minutes a day, totaling 60 hours of practice.

FAAM coaching. The first FAAM coaching session initiated the intervention phase of the study. In preparation for the coaching session, the practitioner used the FAAM coaching manual to develop intervention strategies for the family that addressed the child's primary difficulties with bimanual task engagement. The interventionist met with the caregiver and child for 60 minutes during a mutually agreed-upon day and time of the week. The appointment was determined based on the bimanual goals for intervention and the day and times in which they naturally occur (ex. for a goal of eating with both hands, the practitioner scheduled to visit within the timeframe of the family's typical breakfast, lunch, or dinner time).

The practitioner referred to the FAAM Guideline to determine the appropriate level of engagement with the caregiver and the child. The FAAM Guideline supported the practitioner with navigating through challenges that may occur during intervention based on changes within the psychosocial dynamics of task completion. This includes level of motivation and incentive for completing task, attention to the task, and self-efficacy for task completion. The practitioner taught the caregiver how to modify task approach, model application of the task modification with the child, then coach the caregiver through task execution while practicing with the child, as outlined in the FAAM Guideline. At the end of the coaching session, the practitioner provided the

caregiver with a list of specific activities that could be practiced throughout the day within the context of their naturally occurring activities to achieve similar motor outcomes. The activities were based on items readily available in the home of the family. The caregiver was provided with a weekly strategy reference form for support (See Appendix L). The second coaching session of the week served as a review session. The practitioner gave the caregiver time to provide feedback on strategy use and personal experiences with intervention management, and to answer any questions about strategy techniques. When appropriate, the practitioner provided the caregiver with methods of increasing the practice intensity.

FAAM intervention. The caregiver and child were encouraged to begin FAAM practice at the end of the first coaching session. The caregiver was provided with the FAAM Daily Activity Log in order to log the activities or routines in which the FAAM strategies were used throughout the day. The caregiver and child practiced the strategies for a target of 90 minutes per day, 5 days a week. The caregiver was given the opportunity to communicate with the practitioner at the end of the day through the reflection portion of the daily log. The caregiver was given the option of referencing the FAAM strategy form or video taken during the coaching session if questions about fidelity of strategy use arose.

Intervention mid-testing. At 4 weeks, the PSI-4-SF and the Ease of Caregiving for Children Scale were given to the caregiver to monitor changes in stress levels. In addition to the two measurements, the caregivers submitted additional 3-5-minute videos to examine progress towards each bimanual goal.

Intervention post-testing. The post-testing took place virtually immediately following the 8-week intervention period. The caregiver was directed to fill out the self-reported measures independently and return them no later than 1-week post-intervention. The measures submitted included the Mini-CHEQ, the COPM, the Ease of Caregiving Scale, the PSI, and the Caregiver Satisfaction Survey. After completing the self-reported measures, the caregiver recorded the child performing the bimanual task goals identified on the COPM to compare observable changes in approach to the activity. Consistent with pretesting, the video was recorded for 3-5 minutes per activity at three different time points during the week.

Chapter IV

RESULTS

The purpose of this study was to test the feasibility of the Family Activity Adaptation Model (FAAM) clinical guideline in coaching families to develop new daily habits that support greater bimanual functioning.

Aim 1

The first aim was to develop a manualized clinical guideline (Family Activity Adaptation Model-FAAM) to coach families to develop daily activities and routines that facilitate functional bimanual skills in young children with Hemiplegic Cerebral Palsy (HCP). The results of the FAAM pilot study supported the foundational development of the FAAM Manual (see Appendix B). The current study used the FAAM Activity Analysis during caregiver and child training to further define the factors needed for successful activity performance and highlight similarities and differences among participant needs. Table 4 provides an example of FAAM Activity Analysis findings for the goal, occupation, values and beliefs, context supports and challenges.

Table 4

FAAM Activity Analysis Results

Goals	Occupation	Values, Beliefs and Spirituality	Context: Activity Supports	Context: Activity Challenges
Pouring a glass of milk Stabilizing bowl while eating food Putting straw into juice box Stabilizing food while cutting with knife	ADL : Eating	Greater independence, more bimanual functioning Self-help development	Personal: Prior personal abilities, Eating/drinking more independently (using the less affected side) Physical: The chair, table utensils that support function Social: Social interactions with family	Personal: Prefers to do alone, can get frustrated Temporal: Not always fits the family schedule to practice on this Social: Family schedules can limit social interactions, attention span can be limited
Pulling down shirt with both hands Putting on socks with both hands Pulling up pants with both hands	ADL: Dressing	More independence More confidence In dressing	Physical: Usually, larger sizes Physical: Various sizes available Personal: Enjoys dress up and costume activities	Personal: Uses the less affected side to do the activity Personal: Difficulty in grasp, extension of arm and supination Personal: Able to do it with more supports for body (lying down)
Detach Legos with both hands Squeezing and pushing play dough with both hands Holding shield in left hand while playing sword game Cutting shapes out of paper	Play	Greater play independence Play with siblings Play with peers Skills for school	Personal: Enjoys play, preferred activities Social: Enjoys playing with others Temporal: Time to practice with play and school activities	Personal: Difficulty grasping and hand extension Personal: Prefers not to use the affected hand Social: Attention span is short

The common goals across areas of occupation are illustrated: mealtime goals often involved stabilizing eating utensils or items, common dressing goals included pulling up/down or on/off a shirt, pants or socks. The playtime goals involved the most variety and input based on the child's interests. The values associated with mealtime and dressing were reported by caregivers as important to increase the child's independence, self-help skills and confidence. The values related to playtime were reported as more important for playtime with siblings, peers, and involvement in school activities.

Similarities of context supports included the availability of items for use in the environment, an existing ability to engage in the task, and a personal preference for the selected tasks. Frequent activity challenges reported were a limited attention span, family schedule limiting socialization or practice time, and a preference to perform the task unimanually. A summary of the responses and a thematic analysis of each reported item were created using NVivo software. A line-by-line analysis was also completed by a person independent of the study. Figure 5 presents word cloud representations of the common themes observed with the reported values and beliefs (on the left) and the reported social demands of each goal (on the right).

Figure 5

Word Cloud Representations

Greater independence, self-help development, and bimanual functioning were the major values and belief themes reported across each of the goals. Specific values and belief themes reported included increasing confidence with task performance, developing play skills with siblings and peers, developing school-related skills, and transitioning between dressing outdoor and play routines. Major social demand themes found with each goal

included the ability to imitate and follow prompts of the caregiver, and following established rules or etiquette associated with the task. Some specific demands included sustaining attention with mom or dad while engaging in goal-directed practice with chopping vegetables or fruits, cutting paper, pulling up pants, or putting on a jacket and shoes before leaving the house. Examples of social demands with siblings or family members involved remaining at the table or in the play area to follow instructions or take turns while engaging in play with playdough and following new rules for pretend play with dolls or a sword duel.

Aim 2

The second aim was to examine the feasibility of implementing the FAAM in home settings while using Telehealth. The researcher analyzed this goal in two parts. First, the researcher looked at the feasibility of the training and supervision session with the caregiver and the child. Using the FAAM Daily Activity Logs, each participant rated on a scale of 1 (extremely easy) to 7 (extremely difficult) how easy it was: (1) to fit the FAAM strategies into their daily routine, (2) for their child to accept the new strategies, and (3) to understand strategy use. Figures 6, 7 and 8 show the median response to the FAAM daily practice feasibility as reported in the FAAM Daily Logs per participant per week.

Figure 6

Response to the FAAM Daily Practice Feasibility: "Easy to fit in Schedule"

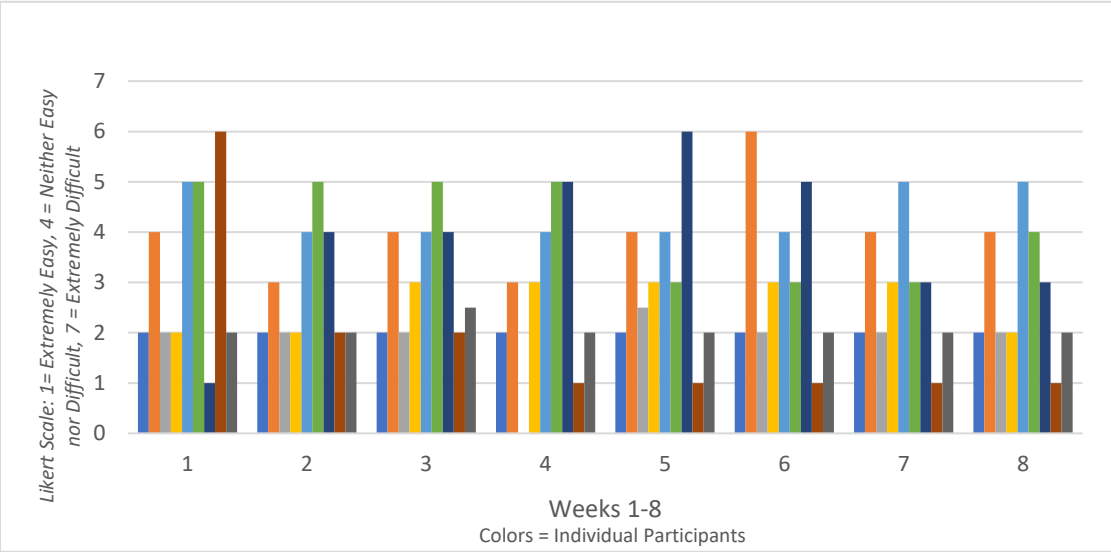


Figure 7

Response to the FAAM Daily Practice Feasibility: "Easy for Child to Accept"

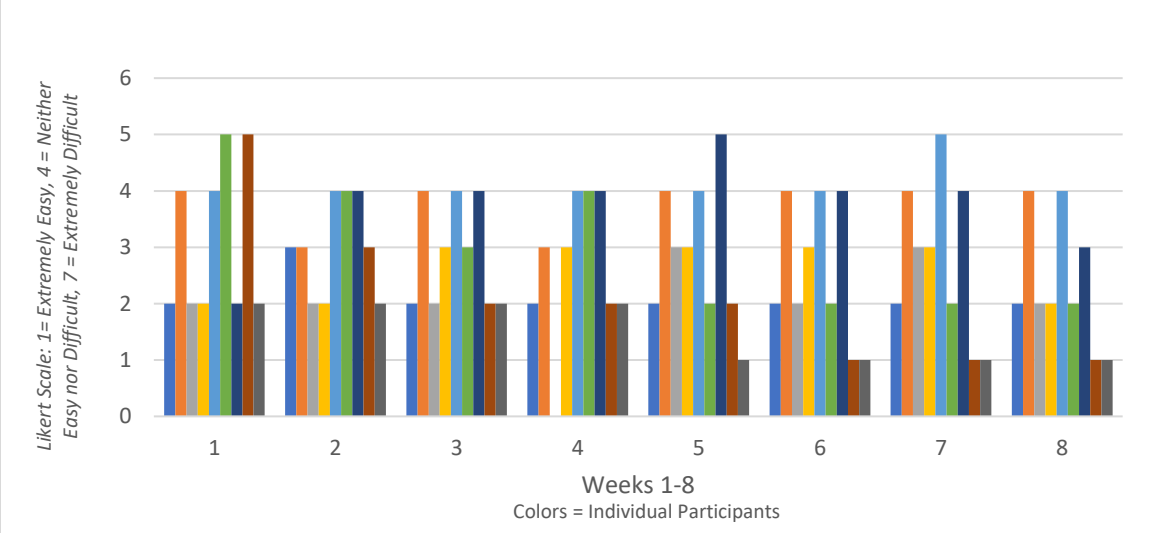
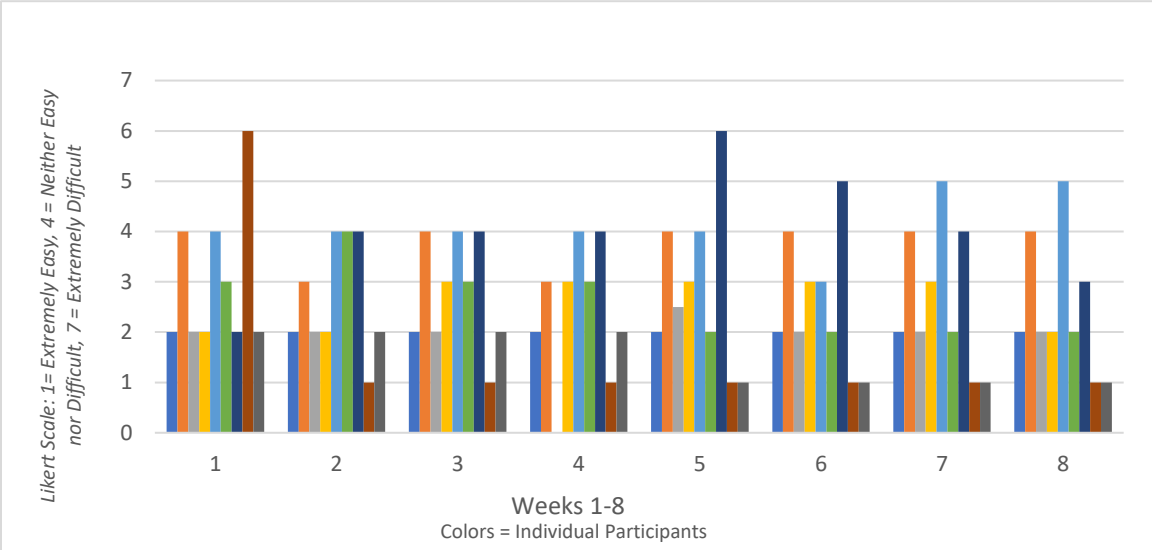


Figure 8

Response to the FAAM Daily Practice Feasibility: "Strategy Use and Understanding"

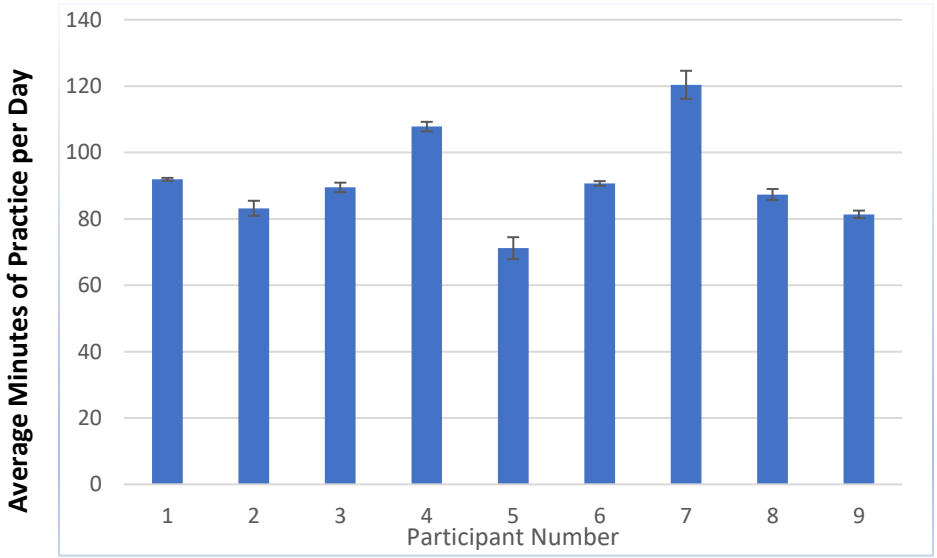


Across 8 weeks, most families appeared to find it moderately easy, or neither easy nor difficult to fit FAAM strategies into their everyday life. During the first week 3 families experienced some difficulty, and at the end of 8 weeks, 1 family expressed some difficulty with incorporating strategies into their schedule. The majority of caregivers reported that it was somewhat easy or neutral (neither easy nor difficult) for their children to accept strategy use throughout the study were accepted strategy use. Two participants found it slightly difficult in the beginning of the study, and 1 participant experienced some difficulty during weeks 5 and 7; however, by the end of the intervention all caregivers reported child strategy acceptance. When analyzing strategy use and understanding, most of the caregivers reported either neutral or slightly easy understanding. During weeks 1 and 5, one caregiver experienced moderate difficulty, and during weeks 6-8 one caregiver experienced slight difficulty with strategy use. Changes in ease of strategy use due to "life events" differed by each family. A tally of FAAM

coaching/supervision session attendance was taken from 17 total training(coaching) sessions; three participants attended 14 training sessions and six participants attended all 17 sessions. The three participants who missed three training sessions reported family emergencies at the time of the missed session (two children were temporarily hospitalized, and one caregiver was pregnant and required a prioritized wellness appointment). Second, the researcher assessed the caregiver's and child's ability to adhere to the guideline implementation requirements. Figure 9 illustrates the average daily practice of each participant per week across 8 weeks.

Figure 9

Average Daily Practice of Each Participant Per Week Across 8 Weeks



Average practice per day for each participant ranged between 70-120 minutes per day, with an average practice of 91.75 minutes (SD 7.069) per day across participants across the study. The highest amount of practice reported in one day was 185 minutes, an d the lowest reported practice in one day was 30 minutes. The participants held "make-

up" practice time to account for the days where lower overall practice time was reported. Across 8 weeks, no participants missed logging and all practice days were accounted for (40 logs submitted per participant in total).

Aim 3

The third aim was to explore the preliminary effectiveness of the FAAM to improve bimanual functional skills (as reported by the caregiver). The researcher used the COPM to look at changes in bimanual functional goals from pretest to posttest. The caregiver selected goals within the categories of playtime, mealtime, and dressing. The dressing goals included putting on jackets, t-shirts, socks and shoes, and pulling up or down pants. The mealtime goals involved stabilizing plates, bowls, or food containers; cutting food with utensils; and preparing desired beverages. The caregivers selected playtime goals with greater focus on the interests of the child, and included bimanual play with playdough, Legos, baby dolls, sword and shield, and cutting activities. The specific goals are outlined in Table 5. Then, the caregiver rated the importance of the goal on a scale of 1 (least important) to 10(most important). Figure 10 illustrates the median caregiver response for category importance.

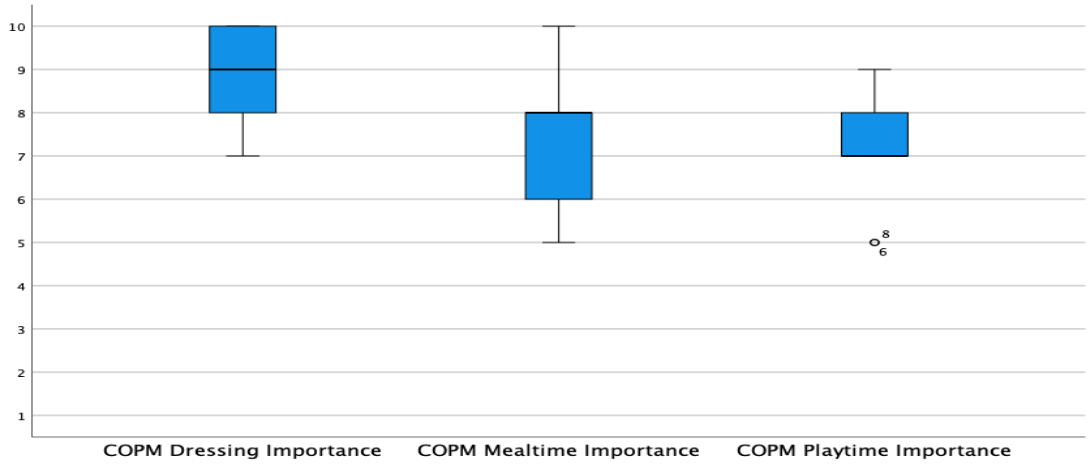
Table 5

Specific Goals

Goal Category	Bimanual Goal
Dressing	• Pulling up/down pants • Putting on socks/shoes • Putting on jacket • Putting on/taking off shirt
Mealtime	• Holding plate/bowl • Carrying plate/bowl • Cutting food w/utensils • Pouring glass of milk • Putting straw in juice box
Playtime	• Making shapes w/playdough • Dressing baby doll • Cutting shapes • Detaching Legos • Holding sword and shield

Figure 10

Median Caregiver Response for Category Importance



The caregivers rated goals within the dressing category as the most important for this study, with the majority of ratings between 8-10. The majority of mealtime goal

importance scores ranged between 6 and 8, and playtime goals between 7 and 8. The caregivers later rated the child's performance of each goal as they perceived it, on a scale of 1 (no performance) to 10 (great performance). Using the same rating scale, the caregivers also rated their level of satisfaction with their child's performance pretest and posttest. A Wilcoxon signed-rank test showed that an 8-week daily HABIT protocol implemented by the caregivers resulted in a statistically significant change in parents' reported improvement of play performance (playtime performance $Z = -2.716$, $p = .007$) and satisfaction with performance (playtime satisfaction $Z = -2.680$, $p = .007$). The median play performance score rating showed an increase from 4 to 8, and satisfaction with performance from 4.5 to 9.0 pre- and postintervention. A statistically significant change in parent's reported improvement of mealtime performance (mealtime performance $Z = -2.675$, $p = .007$) and satisfaction with performance (mealtime satisfaction $Z = -2.677$, $p = .007$) was observed pre and post intervention. The median mealtime performance score showed increase from 2 to 7, and satisfaction with performance from 3 to 8 pre- and post-intervention. Dressing performance and satisfaction with performance also revealed statistically significant change (dressing performance $Z = -2.539$, $p = .011$; dressing satisfaction $Z = -2.524$, $p = .012$). Dressing pre- and post-intervention median scores went from 2 to 8 (dressing performance) and 3 to 9 (dressing satisfaction). Overall, a statistically significant change in total caregiver reported goal performance ($Z = -2.666$, $p = .008$), and satisfaction with performance ($Z = -2.677$, $p = .007$) was seen across all goal categories pre- and post-intervention. Median scores for total performance went from 2.3 to 7.3, and satisfaction with performance went from 3.3 to 8.6 before and after intervention. The Minimal Clinically Important

Differences (MCID) score of 2 for the COPM was met for all COPM scores reported. See Table 6 for COPM Performance and Satisfaction scores.

Table 6

COPM Performance and Satisfaction Scores

Measure	Pretest (Median)	Posttest (Median)	Wilcoxon z-score	Significance (p-value)
Playtime Performance	4.0	8.0	-2.716	p = .007
Playtime Satisfaction	4.5	9.0	-2.680	p = .007
Mealtime Performance	2.0	7.0	-2.675	p = .007
Mealtime Satisfaction	3.0	8.0	-2.677	p = .007
Dressing Performance	2.0	8.0	-2.539	p = .011
Dressing Satisfaction	3.0	9.0	-2.524	p = .012
Total Performance	2.3	7.3	-2.666	p = .008
Total Satisfaction	3.3	8.6	-2.677	p = .007

The Mini-CHEQ (Children's Hand Use Experience Questionnaire) was used to analyze changes in the child's overall bimanual hand use across different age-appropriate daily activities. Table 7 shows the pretest and posttest average median scores.

Table 7

Pretest and Posttest Average Median Scores on Mini-CHEQ

Measure	Pretest (Median)	Posttest (Median)	Wilcoxon z-score	Significance (p-value)
Overall Hand Use	1.8	1.9	-2.106	p = .035
Time to Complete Tasks	1.55	1.9	-2.120	p = .034
Bothered by Reduced Function	2.2	2.8	-2.201	p = .028

A Wilcoxon signed-rank test showed that an 8-week daily HABIT protocol implemented by the caregivers resulted in a statistically significant change in caregiver reported overall ability to use both hands during daily tasks ($Z = -2.106$, $p = .035$). The average median score rating showed increase from 1.8 to 1.9 pre- and post-intervention. A statistically significant change was observed in caregiver reported improvement in time taken to complete to complete daily tasks observed pre- and post-intervention ($Z = 2.120$, $p = .034$). The average median scores from pretest to posttest increased from 1.55 to 1.9, respectively. Statistically significant change was also seen in the caregiver's perception of the child's feelings towards their reduced arm function from pretest to posttest ($Z = -2.201$, $p = .028$). The average median score from pretest to posttest increased from 2.2 to 2.8, respectively.

Aim 4

To examine caregiver burden and satisfaction with the FAAM home program, the researcher analyzed results from the PSI, Ease of Caregiving for Children Measure, and qualitative results from the FAAM Caregiver Satisfaction Survey. For a quantitative analysis of caregiver burden, the PSI was used to assess changes in levels of overall stress in relation to parenting. For the PSI, a decrease in percentile score indicates decreased levels of stress. Table 8 presents the results from pretest, mid-test, and posttest percentile scores.

Table 8

Results from Pretest, Mid-test, and Posttest PSI Percentile Scores

Measure	Pre-Mean (SD)	Mid-point Mean (SD)	Post-Mean (SD)	Significance	Partial Eta Squared
PSI_Parent Distress	74.2 (16.5)	70.1 (20)	67.9 (22.7)	$p \geq 0.05$	.204
PSI_Parent-Child Dysfunctional Interaction	61.2 (10.7)	59.7 (10.7)	55.1 (13.5)	$p \geq 0.05$	.108
PSI_Difficult Child	70 (27.4)	71.4 (14.9)	71 (17.1)	$p \geq 0.05$	.004
PSI_Total Stress	71 (13.4)	68.9 (14.1)	66.3 (16.1)	$p \geq 0.05$	.097

The mean percentile scores for parent distress decreased from pretest (74.2, SD = 16.5) to mid-test (70.1, SD = 20) and posttest (67.9, SD = 22.7). The Parent-Child Dysfunctional Interaction mean percentile scores decreased from pretest (61.2, SD = 10.7) and mid-test (59.7, SD = 10.7) to posttest (55.1, SD = 13.5). The Difficult Child mean percentile scores decreased from pretest (70, SD = 27.4) to mid-test (71.4, SD = 14.9), and remained consistent at posttest (71, SD = 17.1). The Total Stress category mean percentile scores showed a decrease from pretest (71, SD = 13.4), mid-test (68.9, SD = 14.1), and posttest (66.3, SD = 16.1). The researcher used a repeated measures ANOVA test and the Greenhouse-Geisser correction for lack of sphericity in the distribution of the data. Results indicated that the Total Stress scores did not demonstrate a statistically significant change across 8 weeks $F(1,8) = 0.858$, $p = 0.399$, with a $\eta^2 = .097$ (medium effect size).

The Ease of Caregiving for Children measure was used to evaluate changes in the levels of difficulty the caregiver experienced in helping the child perform typical daily

activities. An increase in percentile scores with this measure indicates an increased level of ease in care. The mean percentile scores increased from pretest (54.7, SD = 5.9) to mid-test (57.1, SD = 10.4) and posttest (59.4, SD = 11.6). The researcher used a repeated measures ANOVA and the Greenhouse-Geisser correction for lack of sphericity in the distribution of the data. Results indicated that the pretest, mid-test, and posttest percentile scores did not demonstrate a statistically significant change across 8 weeks $F(1,8) = 1.781$, $p = 0.217$, with a $\eta^2 = .182$ (large effect size) Table 9 shows the overall scores on the Ease of Caregiving for Children Measure for participants over 8 weeks (see Table 9).

Table 9

Scores on Ease of Caregiving for Children

Measure	Pre-Mean (SD)	Mid-point Mean (SD)	Post-Mean (SD)	Significance	Partial Eta Squared
Ease of Caregiving for Children	54.7 (5.9)	57.1 (10.4)	59.4 (11.6)	$p \geq 0.05$	.182

The FAAM Caregiver Satisfaction Survey was used to assess the overall satisfaction with the FAAM home program experience. The caregivers' survey responses were analyzed thematically sentence by sentence within each question and then developed as themes across questions. Four major themes and nine subthemes were developed from the survey responses:

1. Evolving family habits and routines: the caregivers found that practice was made easier when integrated into their daily routine and smaller changes" to daily routines "could get the practice" done (subtheme 1). Another subtheme was that the FAAM approach is "much easier" than traditional therapy, less

stressful and “took away the mom guilt” (subtheme 2). Caregivers also found that “little tweaks could go a long way”(subtheme 3) and were impressed by the results seen in a short period of time.

2. Focus on child’s interests, increase confidence: caregivers reported that the strategies created new opportunities to empower their child and saw “huge increase” in the child’s confidence (subtheme 4). The caregivers felt that the likes and interests of their child were prioritized (subtheme 5); however the friendless of the program “depends” on the characteristics of “the therapist”. The creativity of the practitioner paired with the rapport established between the with the child and family were helpful in encouraging practice (subtheme 6).
3. It takes time and effort: The caregivers found that practice took “forethought and effort” (subtheme 7) but became “easier as time progressed” (subtheme 8). Some caregivers had life events and schedules that also impeded their ability to practice at times (subtheme 9).
4. Program is highly recommended: Overall, the FAAM home program was recommended across participants (subtheme 10). Some parents reported that they have “already started telling people about it” and they “wish we had this approach for him when he was younger.”

Table 10 details the themes along with examples of direct quotes from the FAAM Caregiver Satisfaction Survey.

Table 10

Caregiver Satisfaction Survey Themes, Subthemes, and Participant Quotes

Themes	Subthemes	Participant Quotes
1. Evolving Family Habits	1. "Smaller changes" to daily routines "could get the practice" done 2. Approach is "much easier", less stressful and "took away the mom guilt" 3. "Little tweaks went a long way"	"To me, this was much easier to do than the traditional exercises we are given when we have out-patient therapy… I loved how with this approach, small changes to the way we approached eating, dressing or playing made it so that my daughter could get the practice she needed without having to stop and 'do therapy' or go through a bunch of exercises she had no interest in doing." "Approaching therapy this way was much easier for me—and it took away the 'mom guilt' I've always felt about not being better at doing her exercises all the time…" "We are so very satisfied! To be honest, at first, I wasn't sure how much we would accomplish in two months given that I usually takes him a year to work on a new goal. He can put shoes on over his braces now, which was another amazing feat for him that had been a struggle all his life until now!"
2. Focus on Child's Interests, Increase Confidence	4. "Huge increase" in child's confidence 5. Child's interests were prioritized 6. Caregiver/child friendliness "depends on the therapist"	"We are so happy with the progress we've seen with our child in such a short amount of time. I think the greatest result of this study, for us, has been the huge increase in confidence we've seen in my daughter. She is so proud of herself with how well she can use her 'lefty hand' and has been showing everyone." "[The Practitioner] is very personable and makes the session all about the child. She takes effort into finding out who she is working with and what they enjoy so that she can incorporate his likes into the therapy sessions and strategies."
3. It Takes Time and Effort	7. "It took forethought and effort" 8. Difficult in the beginning, easier as time progressed 9. Life events/ schedules impeded practice at times	"It was definitely possible for us to adapt to our daily routine. It took forethought and effort but I was incredibly happy with how we could increase the effectiveness of therapy in our everyday activities. It became a little more difficult as my pregnancy progressed but so worth it (weeks 29-37 of pregnancy)." "It required a lot more thought in the beginning to incorporate these new tasks for the first time, but it got much easier with time and we were able to really make it a part of our daily routine." "If I was a stay-at-home parent and if [my child] wasn't in school, then yes, it would be caregiver-friendly. But as a working mom to a school-age child, I found it difficult."
4. Program is highly Recommended	10. The program was recommended across participants	"Absolutely, especially if the parent stayed home." "Absolutely! I have already started telling people about it." "I have always tried to incorporate therapies at home/playground/life and I wish we had this approach for him when he was younger."

Chapter V

DISCUSSION

This study examined if use of the Family Activity Adaptation Model (FAAM) as a clinical coaching guideline would be a feasible tool to support caregivers with developing new habits and routines that improve bimanual hand use in children with hemiplegic cerebral palsy (HCP). Nine caregivers participated in a virtual 8-week intervention that included engaging bimanual intensive training (HABIT) within the context of their normal everyday activities 90 minutes a day, 5 days a week, and coaching/supervision of practice 2 times per week over the course of 8 weeks. The processes modeled in the pilot study produced a foundation for the FAAM Guideline and were further refined by the strategies and techniques used in this study. Results from the study also showed that participation in the FAAM home program was feasible for all families as they all adhered to FAAM Guideline expectations for supervision and practice. The intervention supported all children with caregiver-perceived development and satisfaction with development of bimanual motor skills. Changes in levels of caregiver stress and burden throughout the study were unclear; however, caregivers reported overall satisfaction with the FAAM home program.

Development of the FAAM Manualized Guideline

The findings from the FAAM Activity Analysis contribute to the development of caregiver-directed, intensive-motor training home programs for children with hemiplegic cerebral palsy (HCP) delivered using a family-centered approach. Consistent with previous home-based studies using HABIT in the home setting (Ferre et al., 2015; Ferre

et al., 2017), the FAAM uses principles of motor learning within play and functional activities to support development of bimanual motor skills. The motor learning strategies were developed by the practitioner and shared with families during weekly supervision. To date, there is no known clinical standard for the process of strategy development or for coaching the caregiver and child with strategy use. This study adds a step-by-step guide that may be helpful for practitioners to analyze systematically and determine necessary strategy adaptations that remain true to the fidelity of the intervention, as well as to coach families within the context of each child's ability and the family's natural routines and environment. This is also in contrast to previous studies, where HABIT practice was directed by the caregiver and took place outside of the family's normal daily routines (Ferre et al., 2015; Ferre et al., 2017).

Consistent with previous studies involving family-centered practice, intensive motor training, and parent coaching with children who have CP (Morgan et al., 2014; Morgan et al., 2016), the practitioner collaborated with the family to develop goals. The parents were coached through general motor task analysis and encouraged to take advantage of naturally occurring practice activities within their day to practice motor strategies. The strategies described in these studies were applied to families of infants (3-6 months) and largely determined by the treating practitioner where motor interventions used varied per family (ex. mCIMT, weight bearing, concentric/eccentric exercise, manual assistance, bimanual intensive training), while practice intensity was determined by the family. The FAAM adds a guide for specific clinician support strategies that include structured family orientation, activity analysis and adaptation, structured guide for caregiver coaching and engaging the motivation and attention of the child, and a

specific focus on HABIT techniques (eliciting natural, spontaneous engagement of affected hand as an assisting hand, whole-task and part-task practice, task grading, shaping the environment, increasing task complexity) and suggested consistent dosing for bimanual practice intensity (90 minutes per day, 5 days per weeks for at least 8 weeks) for young children with HCP (ages 3-7years).

Feasibility of the FAAM via Telehealth

All nine families who completed the study demonstrated the ability to incorporate FAAM practice throughout their daily activities while receiving all training and coaching through Telehealth. This finding was consistent with previous literature using HABIT training and Telehealth (Ferre et al., 2015; Ferre et al., 2017), in which 12 families successfully completed the home program. Ferre et al. (2017) also reported challenges with participant attrition (25%), whereby caregivers experienced difficulty with the demands of the practice schedule (2 hours/day, 5 days a week, for 9 weeks or 90 hours total outside of daily routine), and recommended future consideration of studies with a distributed model of practice over time. The FAAM provides the first known attempt of this consideration, with practice occurring 1.5 hours a day, 5 days a week for 8 weeks or 60 hours total within the context of natural daily routines. The researcher chose to target 60 hours of practice for the feasibility study to determine the minimal dosage of practice that maintains both feasibility for families and a level of intensity found to be effective in improving bimanual hand use in early HABIT studies in camp settings (Charles & Gordon, 2006; Gordon et al., 2007). The FAAM program had a 90% retention rate after enrollment, with n = 1 who could not continue with the study due to a scheduling conflict that overlapped with a previously scheduled treatment.

The FAAM starts with the process of setting goals using the Activity Analysis as the primary tool. The Activity analysis examines the area of occupation, values and beliefs associated with participation, contextual support and challenges: personal, physical, social, cultural, temporal and virtual. Parents learn how to look at a daily activity as a goal with social expectations, contextual supports and therapeutic benefits. To our knowledge this is the first framework to develop a systematic training of this process.

The addition of caregiver coaching and training 2 times per week for 60 minutes using Telehealth may have been helpful in maintaining home program adherence and acceptability as well as treatment fidelity. Many intensive motor home programs for children with HCP found to be effective in the literature using either mCIMT, HABIT, goal-oriented intensive-motor training or occupational therapy included in-person supervision with a practitioner at least 1 time per week (Chen et al., 2013; Eliasson et al., 2011; Ferre et al., 2015; Gelkop, 2015; Morgan et al., 2014, Morgan et al., 2016; Sakzewski et al., 2015; Wallen et al., 2011). Caregiver-directed HABIT (Ferre et al., 2017) is the first home-based intensive motor training program known to use Telehealth supervision and contributed the lack of change in bimanual skills potentially to the change in supervision from in-person (Ferre et al., 2015) to Telehealth as well as the change in supervision to questions of treatment fidelity. The FAAM protocol added structured caregiver training and coaching through a manualized process of activity selection, adaptation, problem solving through behavioral challenges, practice, and reflection. The coaching occurred through Telehealth 2 times per week as a response to the potential need for additional caregiver support with accountability and protocol

adherence or fidelity. The preliminary results of this study suggested that intensive-motor training programs with supervision delivered through Telehealth may be as helpful as in-person supervision in maintaining intervention feasibility when a coaching approach is used (Camden et al., 2020).

Improvement in Perceived Bimanual Functional Skills

The improvements in bimanual functional goals from pretest to posttest using the FAAM intervention reached statistical and clinical significance, exceeding the Minimal Clinically Important Differences (MCID) of two points on the Canadian Occupational Performance Measure (COPM) for both goal performance and satisfaction with goal performance. The COPM has been used by motor-based home programs for children with CP to measure parents' perception of goal performance and yielded similar and consistent results (Ferre et al., 2015; Ferre et al., 2017; Morgan et al., 2014; Morgan et al., 2016; Novak et al., 2009). Measurement of perceived bimanual hand use across activities in HABIT camp-based studies (Bleyenheuft, Arnould et al., 2015; Bleyenheuft et al., 2017; Brandao et al., 2014) have been measured using the ABILHAND-Kids (Arnould et al., 2004); however, this measurement was not appropriate for this study because it has not been validated for use in children under the age of 6 years. The CHEQ (Skold et al., 2011) has also been found to be a reliable and valid measurement of bimanual hand use and experiences with hand use in daily activities for children 6-18 years old. The mini-version of the CHEQ was used for this study because it is the only known subjective measure of bimanual activity performance to date. The research only analyzed raw score differences from pretest and posttest because this version of the CHEQ has not yet been tested. Restrictions posed by the worldwide COVID-19 pandemic prevented the

practitioner from administering objective bimanual motor measurement, specifically the Assisting Hand Assessment (AHA), as in previous HABIT home-based studies (Ferre et al., 2015, Ferre et al., 2017). Personal communication with the developer of the AHA assessment confirmed to date that the tool has not been validated for use in a Telehealth setting (L. Krumlinde Sundholm, personal communication, May 7, 2020). Despite these challenges, the goal of this study was to evaluate the feasibility of the guideline and its significance from the caregiver's perspective, given that it is still in the phase of testing feasibility. Results from both the COPM and the Mini-CHEQ pointed to the caregiver's perceived effectiveness of the program and overall impact of the intervention on their child's functional abilities. These insights will be used to inform future effectiveness studies using the FAAM.

Caregiver Burden

The FAAM aims to support families with creating new daily habits that encourage greater bimanual functioning. The FAAM protocol adds to the intensive home program literature on structured methods for collecting detailed characteristics of each family and psychosocial measurements of caregiver burden. This information was used to examine how the intervention impacted the caregiver and child dynamic. Previous home-based HABIT studies found that collecting this information may have been helpful in supporting successful intervention completion (Ferre et al., 2015; Ferre et al., 2017). The information was specifically used to understand the interactions between caregiver characteristics (ex. employed vs. stay-at-home, stress levels, number of siblings) and child characteristics (preferred and non-preferred activities, age, level of impairment) and inform home program strategy development. These methods were consistent with studies

done in the early intervention with families of infants at high risk for CP (Morgan et al., 2014; Morgan et al., 2016), in which detailed family characteristics were collected and family mental health was monitored using Depression and Anxiety Stress Scales-21 (Lovibond & Lovibond, 1995). Scores from the Parenting Stress Index (PSI-4-SF) and the Ease of Caregiving for Children measure were examined at pre-, mid-, and posttest solely to monitor potential changes in overall caregiving burden while using the FAAM. While there was no statistically significant difference in total caregiver stress scores and ease of care scores from pretest, mid-test, and posttest, raw total stress and ease of caregiving percentile scores decreased across both measures. Total scores from both the PSI-4-SF and the Ease of Caregiving for Children measures also generated a medium to large effect size and will inform future power analysis for FAAM effectiveness studies. Resources for professional support were offered to all caregivers who had raw scores above the 90th percentile.

Caregiver Satisfaction

Overall, qualitative results from the FAAM Caregiver Satisfaction Survey reported the FAAM to be a feasible and favorable intervention with a positive impact on their child's functioning. Home programs are typically designed to support families with long-term support beyond the clinic and when clinic-based therapy is not readily available, affordable, or accessible (King & Rosenbaum, 2004; Novak & Cusick, 2006; Novak et al., 2009). Caregivers in the study reported that the FAAM strategies were accessible and "much easier to do than the traditional exercises we are given when we have out-patient therapy." The FAAM intervention provides a cost-effective, culturally relevant intervention for families that comes at a time where access to or continuation of

services therapeutic services is critical to supporting functional development. Prior to the start of the global COVID-19 pandemic, all caregivers and children were receiving occupational therapy, physical therapy, or other types of supportive motor therapies through private and/or school settings. Six of the nine families in the study reported a temporary or extended disruption in regular therapy services. The FAAM was able to reach families across diverse settings and cultures within the United States. Home-based intensive bimanual motor training protocols in the literature also successfully expanded reach across states using Telehealth (Ferre et al., 2017). The FAAM gives an additional element of reach to Telehealth-based bimanual intensive training as the protocol has a specific focus on practice only using items that are accessible in the child's natural environment, whereas in previous studies, the use of items in the natural environment was encouraged but not the main focus of intervention (Ferre et al., 2015; Ferre et al., 2017; Morgan et al., 2014, Morgan et al., 2016). Another family highlighted "it was nice to have a therapist see what we had in our home that could be adapted or tweaked in some small way to turn it into an easier way for my daughter to practice, or a better way for her to sit at the table, things like that that you don't get from going to therapy at a clinic."

Limitations and Future Direction

There were some limitations to implementing the FAAM using Telehealth. The first was the impact of technology on the flow of the intervention. Depending on the family and their selected internet provider, intervention sessions were sometimes interrupted. When this occurred, the practitioner completed strategy communication via email or postponed the session to a later date during the week. Also, with the current

impact of COVID-19 on child routines, exposure to screen time occurred more frequently than typically reported for most families. The study began between a transition from summer break to a new school year, when some families were faced with adopting a completely virtual 3-6-hour school day. This led to some children experiencing screen-time "burnout" and decreased attention and motivation during session time. Development of a systematic strategy for navigating technological difficulties and alternative options for weekly training/coaching is warranted in future studies to prevent potential frustration or loss of motivation from the caregiver or the child. One suggestion may be to provide a break for the family by designating the second coaching session of the week as an optional "brief check-in" as opposed to a full 60 minutes of interaction.

Another challenge for families included the responsibility of paperwork and daily activity logging in multiple different locations. This was consistent with findings from the pilot FAAM study, where caregivers suggested elimination of physical paperwork and a transition to an electronic system for logging with condensed paperwork would be more feasible. While all paperwork was provided electronically, caregivers did not have full editing access to all electronic file types used (ex. Adobe Acrobat) or use of a scanner. Future FAAM studies will include transition from use of multiple internet-based files to use of a FAAM intervention planning mobile application. This comes at the suggestion of the caregivers who felt a combination of "brief contact with therapists" for communication, daily activity logging, practice strategies, activity adaptations, and child progress would be most conveniently communicated on one central platform.

FAAM practice strategies were encouraged to take place across mealtime, playtime, and dressing routines; however, families were also encouraged to report

practice with “other” activities that occurred within their natural routines but did not fall directly into one of the three suggested practice routines. Overall, COPM importance ratings showed that caregivers reported dressing goals as the most important; however, findings from the FAAM Daily Activity Logs showed that dressing time was reported within the smallest blocks of practice time (practice time ranged from 1-20 minutes). Future studies should expand methods for developing greater dressing practice opportunities in the FAAM Guideline as dressing is of high priority to families. “Other” practice activities were not rated by caregivers as they were not predicted intervention activities; however, some activity examples included swimming, yoga, riding a bike or scooter, household laundry, washing dishes, tending to farm animals, baking, grocery packing, fruit picking, and gardening. “Other” practice activities were consistently reported weekly across participants. Data regarding “other” practice opportunities during the day should inform the development of the FAAM Guideline to measure the importance of practice activities that are meaningful to families outside of mealtime, playtime, and dressing.

While the FAAM program had 100% caregiver satisfaction and was recommended by all caregivers, practice strategies were challenging for some families managing multiple longer-termed life events. The activities were described as sometimes challenging and these caregivers “found it difficult” to complete as a “working” caregiver “to a school-aged child.” Another caregiver was pregnant during the time of the study and was “juggling morning sickness, appointments, working from home schedule and online school and caring for family members.” This finding draws attention to questions in previous studies of types of families that may be most suitable for intensive-motor

training home programs (Ferre et al., 2017). Future studies further analyzing the impact of family characteristics and treatment effectiveness may be helpful in supporting clinicians with determining the most appropriate use of the FAAM Guideline or if the Guideline is appropriate for the family at the given time. One caregiver who felt she needed help with strategy use outside of supervision took the initiative with difficult situations by "making sure that we [were] using language that requires ALL of us in the family to do what we expect of him." One potential solution to this challenge for future studies may be adding a structured process for inclusion of a second caregiver or multiple family members in the FAAM training process for purposes of intervention carryover when the primary caregiver is not present.

Additional limitations of this study were that the researcher used a small convenience sample of participants from a CP parent support group. It is possible that this sample was predisposed to similar treatments in the past and thus may have been a self-selecting group of caregivers who were more willing to complete interventions such as the FAAM. Also, as this was a feasibility study of the intervention protocol, no objective motor measurements were used to determine changes in overall bimanual motor skills. After completion of a mobile application, future studies will move towards determining appropriate sample size and producing effectiveness studies. As promising results were observed cross-culturally with geographic location and socioeconomic status, the researcher looks forward to developing the FAAM for clinician use and family benefit internationally and in developing countries where families have limited resources and access to services.

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Appendix A

Pilot Study

Feasibility of the Family Activity Adaptation Model in Improving Bimanual Hand Use in Children with Hemiplegic Cerebral Palsy

Pilot Study

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Conceptual Framework

A Caregiver Training Protocol (Family Activity Adaptation Model-FAAM) was developed as a service-delivery model for practitioners to manualize and guide creation of evidence-based home programs that support development of bimanual hand use in children with hemiplegic CP. The model aims to support the development of motor skills in the context of everyday activities and social interactions. The FAAM is a detailed practitioner guideline that focuses on coaching families to adapt a modified approach to their normal daily activities and routines that facilitates bimanual hand use. The FAAM "family" is identified as the child and the primary caregiver supporting the child through the selected activities in their natural environment. The FAAM is specifically designed for children between the ages of 3 to 7, within MACS levels I, II and III. This age range was most appropriate for initial FAAM development as it covers the preoperational stage of cognitive development, where children are typically still dependent on their caregiver for direction and decision making, and are not fully using cognitive operations (Piaget, 1990). Children at MACS levels I-III were tested with initial development of the FAAM as they are able to actively engage in problem solving with both hands at varying levels of independence. Children within these levels of classification have also been consistently tested with previous bimanual intensive training protocols (Charles & Gordon, 2006). The FAAM is based in the framework and literature of occupational therapy, and further supported through evidenced-based protocols within motor learning and speech-language pathology literature.

Goal Setting and Activity Analysis

The FAAM provides a guideline for goal development between the family and the interventionist. During goal identification, child and caregiver priorities for bimanual hand use within their home-based daily activities and routines are identified. Goal setting with the family is also used to facilitate greater functioning in the family's current activities and routines, as well as promote child autonomy and independence (Wulf & Lewthwaite, 2016). This is achieved through in-depth interview and discussion between the family and the interventionist. We use the Occupational Therapy Practice Framework (OTPF) to organize goal setting and support the activity analysis process. The OTPF describes the guiding principles of practice used by occupational therapists and other individuals contributing to the field of occupational therapy. (American Occupational Therapy Association, 2014). The specific domains of focus used in the FAAM include occupations, client factors, performance skills, and contexts and environments. Occupations are life activities that are considered meaningful to the individual (American Occupational Therapy Association, 2014). The selected goal is categorized according to the most relevant occupational subdomain. Occupational subdomains for children include activities of daily living (ADLs), instrumental activities of daily living (IADLs), education, play, or social participation. ADLs are daily activities that target self-care and may involve bathing, toileting, dressing and feeding. IADLs in the context of the FAAM are more complex activities that support life in the home such as pet care and religious and spiritual activities. The education and play subdomains focus on learning activities and activities that are enjoyable for the child respectively. Social participation in the

FAAM is captured through involvement or sharing in activities (Law, 2002) with others that involves family, peers and friends.

The FAAM Activity Analysis provides a structure for analyzing each activity or routine embedded within the goals outlined with the family during the goal identification process. It initiates the evaluation process of the FAAM, and information collected during this process is used to form an individual profile for each family. The occupation, client factors, context, environment, and performance skill domains are outlined in detail and are determined by interventionist observation of task performance in the client's natural environment. Client factors for the FAAM are identified as family values, beliefs and spirituality connected to the activity, upper limb motor performance skills and cognitive demands needed to support task execution. FAAM context and environment factors are determined by assessing specific personal, physical, cultural, social, temporal and virtual contexts that may support or challenge task performance. The information collected in the activity analysis develops a modified guide for sequencing and timing of task execution based on observation of the family's natural routine and identified factors that may impact task performance.

Family Support (FAAM Coaching)

The FAAM framework supports interventionists with the process of coaching the child and caregiver through activity practice and performance. To encourage motivation and attention for practice using the affected hand, The FAAM promotes engagement in normal daily activities, tasks that are identified as meaningful to the child and family, and social comparative feedback. The OPTIMAL (Optimizing Performance through Intrinsic Motivation and Attention for Learning) theory of motor learning highlights that

conditions that enhance performance expectancies, encourage of learner autonomy, and create an external focus of attention on task goal may lead to greater coupling of the individual's goals to their motor actions and optimize overall motor learning and performance (Wulf & Lewthwaite, 2016). Literature on participation in occupations of everyday life (Law, 2002) and the OPTIMAL Theory emphasizes the importance of providing choices that provide the "just right challenge" for clients. The specific FAAM strategies that target learner motivation, autonomy and external focus of attention include: increasing control over bimanual task conditions, providing choices for bimanual tasks and negotiating structure of tasks, providing practice conditions that encourage task success and emphasizes successful performance, and directing the individual's attention to the task goal versus use of both hands. Children's motor skills are utilized and refined in the social context. Their engagement and interaction with tasks is only meaningful in the context of activities that are meaningful and relevant to their interests. Therefore learning of new motor skills and cannot be fully defined or understood without considering the social cognitive and attentional factors that influence motor actions. According to the OPTIMAL theory of motor learning, intrinsic motivation that promotes feelings of self-efficacy can affect motor learning and performance on tasks. (Wulf & Lewthwaite, 2016). Creating opportunities where learning is empowering for the child and guided by their goals and interests is imperative. Providing social support and feedback further enhances the process of learning. Social comparative feedback emphasizes the use of positive feedback (regardless of actual results) that suggests individual performance is more effective, or greater than normal or average to enhance motor learning (Lewthwaite & Wulf, 2010). The FAAM protocol utilizes a real context

specific need that children and families identify and train families to provide the comparative feedback support while the child engages in functional tasks.

Family Support: Teach, Coach & Review

The family support processes of evaluation, intervention, and targeting outcomes are guided by the OTPF, as well as the Teach-Model-Coach-Review (TMCR) instructional approach (Kaiser & Roberts, 2013). The TMCR model has been found in speech-language pathology literature to be an effective, evidence-based method for coaching parents in use of therapeutic strategies. The model is based on principles of adult learning and derived from 6 teaching methods impacting knowledge, skills, self-efficacy, beliefs, and attitudes. The specific TMCR strategies used in the FAAM framework include: teach (introduction of bimanual motor strategies to be learned), model (illustration of bimanual motor strategies taught), coach (practice of bimanual motor strategies modeled), review (evaluation of outcome on motor skills and reflection on strategy to determine next steps) and mastery (assessing fidelity of motor strategy use). The Family Support process of the FAAM summarizes these steps into an ongoing process that includes the coaching principles of engagement and is defined by 3 concepts: Teach, Coach (Modeling, Engaging, Monitoring) and Review. These processes allow the interventionist to share specific modifications necessary for successful task performance with the family, and are based on observation and the findings from the FAAM Activity Analysis.

Hand-Arm Bimanual Intensive Training (HABIT)

HABIT is used as the guiding principle for bimanual motor skill development throughout application of the FAAM home program. HABIT is an evidenced-based

bimanual therapy training protocol found within studies of motor learning. The HABIT creates opportunities for children and youth with hemiplegia to increase bimanual functioning through intensive practice that does not restrain the affected hand and uses child-friendly bimanual activities. The specific principles used in the FAAM focus on: practice intensity, whole task practice, part task practice, task grading, and functional goal training. Practice intensity has been found to be a key ingredient in promoting neuroplasticity (Gordon et al., 2007; Friel et al., 2016) and is promoted through provision of a consistent daily practice schedule for families, meeting a 60 hour minimum throughout the course of the program. Whole task practice (practice of the task in a sequential and successive manner continuously for at least 15-20 minutes) is the primary focus for motor practice in FAAM protocol, while part task practice (practicing components of motor skills in smaller segments of time with increasing complexity and repetition) is encouraged as a secondary focus (ex. During task set up or clean up time). The FAAM approach to HABIT application is used in effort to remain consistent with the family's normal routine and modify activity approaches in a manner that allows for lifestyle adaptation within the family's timing.

Improve Daily Activity Function & Bimanual Motor Skills

The FAAM Framework presents a manualized process for service delivery created to support practitioners with a method for coaching caregivers and children in bimanual intensive training that maintains recommended practice intensity for improvement in bimanual hand use and supports the interests, needs and lifestyle of each family. The framework is guided by principles of occupational therapy, motor learning, and speech-language pathology literature. The FAAM combines meaningful occupations,

contexts, client factors, motor performance skills, child engagement, motivation and autonomy, and structured caregiver coaching to support families through intensive home program use. The FAAM combines strategies for family-centered support and key ingredients of bimanual intensive training, specifically HABIT, to produce a service delivery model for home programs that may be effective in improving skilled bimanual hand use within the context of the activity, those similar to the functional activity goal, and overall bimanual hand use.

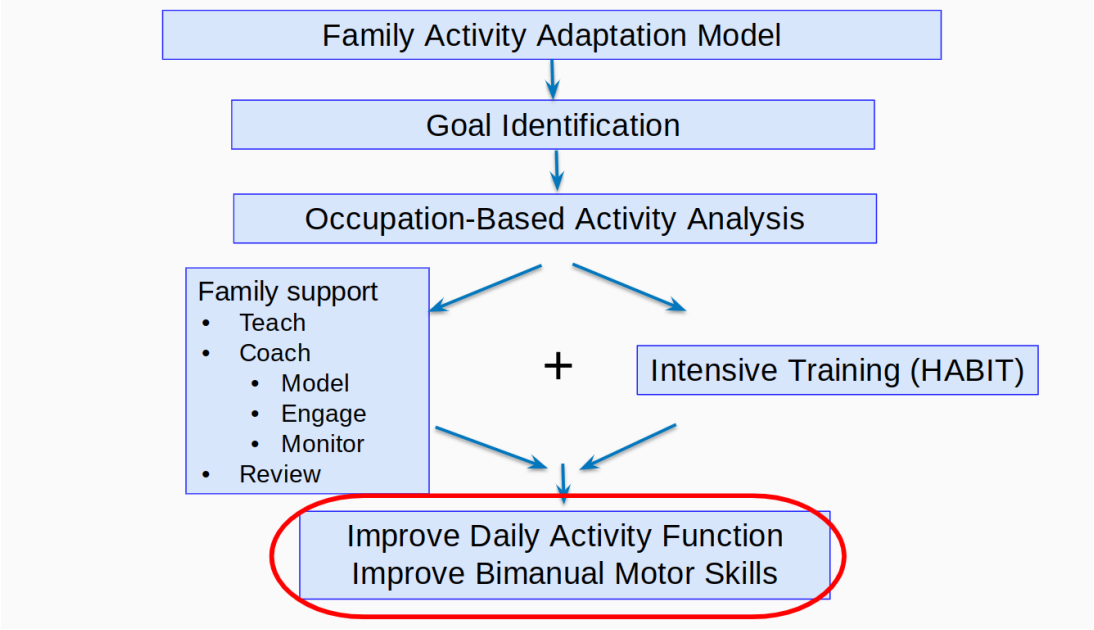

Figure 1 FAAM Framework Flowchart

Methods

To develop a manualized service delivery and intervention protocol, we have followed the methodology suggested by the United Kingdom's Medical Research Council (MRC) for developing and testing complex therapeutic interventions (see Figure 2, Craig et al., 2008). We consider the FAAM a complex intervention because it meets the following specific criteria: there is a variability of outcomes, there is a high degree

of flexibility or tailoring within the intervention, and there is high number and difficulty of behaviors expected by those receiving or delivering the intervention (Craig et al., 2008). Based on this method the development of the FAAM intervention is outlined in four non-linear phases: (1) development, (2) feasibility and pilot testing, (3) evaluation, and (4) implementation. In this dissertation, the pilot study was carried out to examine phase 1 (development) & 2 (feasibility) and the proposed dissertation study will be an extension of Phase 2(feasibility).

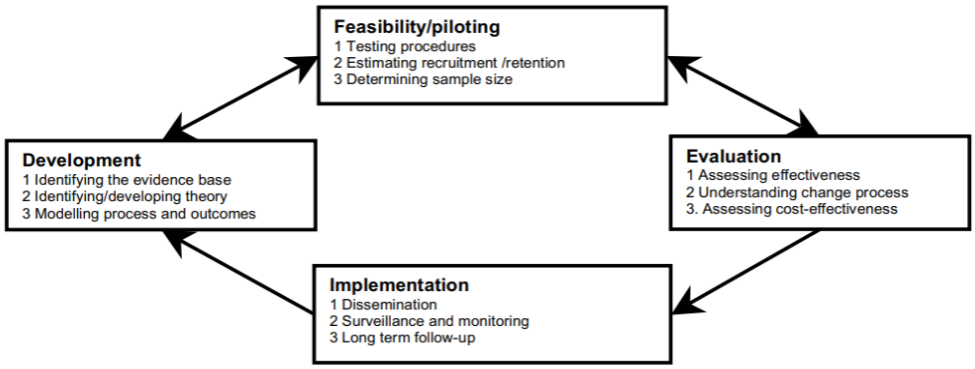

Figure 2 Developing and Evaluating Complex Interventions (Craig et al., 20008)

Pilot Study: Development (Phase 1) & Feasibility (Phase 2)

Phase 1 involves identification and review of existing evidence (see Chapter II, Literature Review), and developing theory (see Chapter III, Theoretical Framework) that support the new intervention, and modeling the intervention to understand impact and areas that may need to be clarified. Phase 2 uses a mixture of qualitative and quantitative methods to test the feasibility of the intervention and includes navigating through intervention acceptability, fidelity, adherence, recruitment and retention. The FAAM presents a new manualized guideline that was developed to guide clinical practice in home interventions for the HCP population. The FAAM also adds flexibility to the

traditional delivery of HABIT (Gordon et al., 2007) to be implemented in home-based settings (Ferre et al., 2017), and modifies the roles and responsibilities of both the therapist and the caregiver.

Purpose.

The purpose of the pilot study was to better understand the effectiveness of the coaching aspects of the FAAM in (1) facilitating modification of daily activities and routines that support children's skill development and (2) supporting caregivers with acceptability, adherence and fidelity of home program use.

Participants.

The participants for the study included children with HCP (n=3) between the ages 3-7 years old with Manual Ability Classification System (MACS) levels I - III and the caregiver or parent of the child participant (n=3).

Recruitment.

Caregivers and children will were recruited via flyer through an agency that services children with special needs (Lee's Developmental Services), as well as through word of mouth by individuals that provide resources to families of children with cerebral palsy (Center for Cerebral Palsy Research, Teachers College Columbia University) Recruitment for this study was approved by Teachers College Columbia University Institutional Review Board (IRB# 18-393). Purposive and convenience sampling was used to select families that met age, presentation (HCP), and location criteria (within the NY Metropolitan Area).

Inclusion/exclusion criteria.

The inclusion/exclusion criteria were based on previous HABIT studies (Gordon et al., 2007; Ferre et al., 2017). Child inclusion criteria included: (1) the ability to grasp and release with the affected hand, and (2) the ability to follow 2-step directions. The inclusion criteria for caregivers was that they were the adult that typically carries out the selected routines with the child. The child's condition was confirmed through an in-person screening. Exclusion criteria included: (1) an inability to grasp or use the affected hand as a stabilizer (2) health diagnoses that are not associated with cerebral palsy, (3) cognitive delays that would prevent the child from following one-step directions, and (4) visual problems that may prevent completion of intervention tasks or testing. Exclusion criteria for caregivers was an inability or unwillingness to participate for the entire length of the intervention.

Study design.

The pilot study followed a mixed methods, single group pre-test post-test design. The study took place for 2 weeks, where caregivers were coached through incorporating HABIT techniques in their daily activities & routines using the FAAM approach. The study involved formal measures (i.e., COPM) and daily logs (qualitative narratives). Baseline measurements were taken with the child and the caregiver prior to the beginning of intervention, and again 1 week post intervention. Caregiver training took place prior to the start of intervention and continued 1 additional day during the second week in the form of coaching/supervision. The child and the caregiver engaged in the intervention for 1.5 hours a day, 5 days a week over the 2 week intervention period.

Outcome measures.

The outcomes were measured using a mix of qualitative and quantitative methods as recommended by MRC guidelines in phase 2 of conducting a feasibility study (Craig et al., 2008). The COPM was used to quantitatively measure outcome (1) effectiveness of FAAM coaching in facilitating development of daily activities and routines that support children's skill development. On the COPM, parents were asked to identify daily activities or routines that are meaningful to them and would like to see improvement with. Then, the parents were asked to rate the importance of each activity on a scale of 1-10. Based on their ratings, parents selected 3 of the most important goals for intervention and rated their child's performance and their satisfaction level with performance on a scale of 1-10. Reports from the COPM allowed the investigator to analyze if the activities and routines developed during coaching had a supportive impact on the bimanual goals of the caregiver and child. This was determined by changes in performance and satisfaction with performance of each goal as reported by caregivers pre and post intervention.

The FAAM Daily Logs, Caregiver Activity Questionnaire and Final Caregiver Questionnaire were used to measure outcome (2) feasibility of FAAM coaching in supporting caregivers with acceptability, adherence and fidelity of home program use. Daily logs were designed as a quantitative (time recorded for the activities) and qualitative (commentary) measure specifically for the FAAM to track the amount of time spent completing each task daily. The logs contain space for the caregiver to write the type of task performed, the time of day (morning, afternoon or evening) how many minutes it took to complete each task, whether the task difficulty was increased or decreased, and total time spent performing activities (out of a target of 90 minutes). A

brief questionnaire is provided at the end of the log where the caregiver will be asked to rate on a scale of 1-5 their ability to fit activities into their daily schedule, how well the child tolerated the activity changes, and ease with consistent strategy use. The FAAM daily logs were modeled from previous home programs using HABIT techniques (Ferre et al., 2017) and were used as a measure of home program feasibility, specifically analyzing fidelity of implementation (extent of program execution), adherence (ability to carry out intervention strategies consistently) and acceptability (perceived and actual ability to integrate activities into daily routines).

The FAAM Caregiver Activity Questionnaire presented a qualitative and quantitative measure of the caregiver's experience with home program use at the end of each practice week. This information was used to assess changes in the caregiver's attitudes towards home program acceptability and identify factors in their environment that could potentially impact program fidelity. For an example, one question asked: "I am able to set up my home in a way that allows me to do this activity easily". The caregiver was asked to rate their responses on an ordinal scale of 1 (never) to 5 (always). Responses rated negatively were used to guide the interventionist in better understanding individual family needs for success and optimal experience with home program use.

Finally, the FAAM Final Caregiver Questionnaire was given at the end of the study as a qualitative measure. The final caregiver questionnaire is an open-ended response form and was used to evaluate overall satisfaction with intervention experience, intervention demand, and feasibility of intervention implementation.

Procedures.

FAAM caregiver training.

Following pre-testing procedures, training in the FAAM techniques took place for 2 days over the course of 60 minutes in the home of each family and included both the child and caregiver. Table 1 summarizes the procedures of the pilot.

Table 1

FAAM Pilot Procedures

Testing & Training	Description & Time
Pre-Testing Caregiver Training	COPM FAAM Activity Analysis FAAM Education Day 1 - 60 Minutes
Pre-Testing (cont.) Caregiver Training	FAAM Education Family Schedule Review Day 2 - 60 Minutes
Intervention	FAAM Coaching - 1x/week for 60 mins FAAM Intervention - 5x/week for 90 mins FAAM Daily Activity Log - 5x/week FAAM Caregiver Activity Questionnaire - 1x/week Weeks 1-2
Post - Testing	COPM FAAM Activity Analysis FAAM Final Caregiver Survey Day 1

Table 1

Caregiver training and pre testing.

Week 0, day 1.

During the first day of training, the caregiver and child completed a FAAM orientation. The caregiver and child received consent and assent forms, educational material regarding the FAAM home program, and completed the COPM to establish bimanual goals for the study. At the end of the orientation, the interventionist asked the caregiver to perform each of the bimanual tasks identified in the COPM for 2-5 minutes while being video recorded, allowing the interventionist to later complete the FAAM Activity Analysis. The FAAM Activity Analysis allowed the interventionist to collect interview observational data about the child's interaction with the bimanual activities that included: activity identification, values, beliefs and spirituality associated with participation, contexts, objects and properties required, social demands, sequence and timing, motor movements required and performance patterns. This data was used to monitor changes in caregiver and child motor and psychosocial engagement during intervention. The specific evaluation factors included motor engagement of hands, duration of activity, needs for parent intervention, and task completion. The interventionist provided the caregiver the option of submitting a video of the child engaging with the task for the children who were not willing to engage in the activity at the time of the orientation meeting.

Caregiver training and pre testing (cont.).

Week 0, day 2.

The final training day included a final orientation overview. The meeting took place for up to 60 minutes and was dedicated a final review with both the caregiver and

the child. During the final orientation overview, the interventionist, caregiver and child reviewed the family's typical weekly routine, detailing activities that would normally take place throughout each day. Based on the schedule provided, the interventionist and family agreed on the times throughout the day that worked best for both the caregiver and child to implement FAAM practice, as well as to receive their weekly coaching visit. The training concluded with a review of any questions the family had regarding the FAAM home program and techniques.

FAAM coaching and intervention protocol.

Weeks 1and 2.

FAAM Coaching & Intervention took place over the course of 2 weeks. FAAM Coaching took place one time per week for 60 minutes totaling 2 hours of coaching. FAAM Intervention will take place 5 days a week, for 90 minutes a day totaling 15 hours of practice (see Table 1)

FAAM coaching.

The first FAAM coaching session initiated the intervention phase of the study. In preparation for the first coaching session, the interventionist developed motor-based intervention strategies for the family to address the child's primary difficulties with bimanual task engagement. This included a review of the baseline video of the caregiver and child engaging in 3 bimanual tasks of greatest priority for intervention as identified on the COPM. The interventionist met with the caregiver and child for 60 minutes during a mutually agreed upon day and time of the week. The appointment was determined based on the bimanual goals for intervention and the day and times in which they

naturally occurred (ex. For a goal of building legos with 2 hands, the interventionist scheduled to visit within the time frame of the child's "free play" time).

The interventionist proceeded to teach the caregiver how to modify task approach, model application of the task modification with the child, then coach the caregiver through task execution while practicing with the child as outlined in the FAAM framework. At the end of the coaching session, the interventionist provided the caregiver with a list of specific activities that may be practiced throughout the day to achieve similar motor outcomes. The activity recommendations were based upon items readily available in the home of the family, and other naturally occurring activities throughout their day. The caregiver was given the opportunity to take notes on intervention strategies for the week and provided with video taken via cellular phone with coverage of their practice session using the FAAM techniques.

Family (caregiver & child dyad) profiles.

Family 1.

Family 1 lived in a ranch style home in a suburban area of New Jersey. Caregiver 1 is a Caucasian woman who is the mother of Child 1 and a social worker by trade. Caregiver 1 worked part time as a cashier while taking care of Child 1, his sibling and their dog.

Child 1 is a 4.5-year-old boy that is living with Unilateral Cerebral Palsy, right-sided hemiparesis. Family 1 reported that Child 1 did not have any co-occurring diagnosis and functioned at a Manual Ability Classification level of III. Child 1 attended school Monday through Friday for approximately 5 hours. After school, Child 1 typically received 1 hour of specialized therapy, including physical therapy, speech language

pathology, occupational therapy and hippotherapy, prior to returning home. Consistent family routines included breakfast, snack time, playtime in the home after leaving school and specialized therapy, dinner, bath time and bedtime. Child 1's family unit consists of one younger sibling (2 years old), one dog, and two parents (2 mothers). Child 1 was primarily supported by one of his mothers, who took him to all of his therapy activities and cared of him, his younger sibling and dog in the home before his other parent (mother) returned home in the evening. Child 1's interaction with his other parent was limited to evenings as she worked during most of the weekday activities reported.

Family 2.

Family 2 lived in a penthouse style apartment in urban New York City. Child 2 was supported by both his nanny and mother (Caregivers 2.1 & 2.2 respectively). Caregiver 2.1 is a Caucasian woman and worked as Child 2's nanny. Caregiver 2.2 is a Caucasian woman who is the mother of Child 2 that worked as an entrepreneur and business executive.

Child 2 is a 3-year old boy living with Unilateral Cerebral Palsy, right-sided hemiparesis. Child 2's family reported no co-occurring diagnosis and was functioning at a Manual Ability Classification level of III. Child 2 attended school Monday through Friday for approximately 3-4 hours. After school hours, Child 2 typically engaged in specialized therapy or enrichment programs ranging from 1-2 hours. Consistent family routines included breakfast, lunch, playtime, dinner, bath and bedtime. Child 2's family unit includes 2 parents (one mother, one father), 1 nanny, and a dog. Child 2's nanny and mother primarily supported him throughout his daily activities. Child 2's nanny spent most of her time preparing, supporting and transitioning him through all of his daily

activities. Child 2's mother acted as a support he engaged in most of his daily activities. Child 2's interaction with his other parent (father) during the weekday activities reported was limited as he worked during most of the given hours.

Family 3.

Family 3 lived in a single family house in a suburban area of New York City. Caregiver 3 is a Caucasian woman and is the mother of Child 3. Caregiver 3 has a condensed daily schedule and was frequently limited with time due to religious observances, as well as transitioning 3 children between various daily activities and routines. Child 3 is a 7-year old boy living with Unilateral Cerebral Palsy, right-sided hemiparesis. Child 3's family reported no co-occurring diagnosis and was functioning at a Manual Ability Classification level of II. Child 3 attended school Monday through Friday for approximately 8 hours and occasionally received private specialized therapy services. Consistent family routines included breakfast, dinner, homework/playtime, bath and bedtime. Child 3's family unit includes 2 parents (one mother, one father), 1 younger sibling, and 1 older sibling. Child 3's care was primarily given by his mother, however his other parent was typically in the home and acted as a support for him and his other siblings during the reported daily routines.

FAAM intervention.

The caregiver and child began FAAM practice after the end of the first coaching session. The caregiver and child were provided with the FAAM daily activity log, where they logged the activities or routines in which the FAAM strategies were used throughout the day. The caregiver and child practiced the strategies for a target of 90 minutes per day. The caregiver was given the opportunity to communicate with the interventionist at

the end of the day through the reflection portion of the daily log. The caregiver was also given the option of referencing video taken during the coaching session if questions regarding fidelity of strategy use arose. At the end of each practice week, the interventionist had the caregiver complete the FAAM Caregiver Activity Questionnaire for feedback on adjustment towards home program use.

Intervention post testing.

The post-testing took place at the end of the 2 week intervention period over 1 day at the home of the family for a total of 60 minutes. The interventionist had the caregiver complete the COPM to gather rating on child performance and satisfaction with performance of bimanual tasks post intervention. The therapist also video recorded the caregiver and child performing the bimanual task goals identified on the COPM for each goal to compare observable changes in approach to the activity. Consistent with pre-testing, the caregiver was given the option of submitting the video to the therapist at a later time if the child was not willing to perform the activity on the day of testing. A final activity analysis was completed by the interventionist to document qualitative changes in bimanual performance. The post-test was completed with the FAAM Final Caregiver Questionnaire.

Results.

The overall purpose of the pilot study was to examine the feasibility of the FAAM and HABIT protocols in families of preschool and school aged children with HCP. The pilot study included 3 families (Tables 2 & 3 summarize participants' characteristics).

Table 2

Family Characteristics

Family	Household Caregivers	Race	Siblings	Primary Caregivers (for FAAM)
Family 1	2 Mothers	Caucasian	1	1 (Mother)
Family 2	1 Mother 1 Father	Caucasian	None (mother is pregnant)	2 (Mother and Nanny)
Family 3	1 Mother 1 Father	Caucasian	2 (2 Brothers)	1 (Mother)

Table 3

Children Characteristics

Child	Age	MACS Level	Affected (Non-Dominant)Hand	Receiving Occupational Therapy?
Child 1	4.5	III	R	Yes
Child 2	3	III	R	Yes
Child 3	7	II	R	Occasionally

Table 3

Pilot goal 1.

The first goal of the pilot was to understand whether the FAAM protocol could facilitate modification of daily activities and routines that support children's skill development. Children and caregivers identified goals within the context of daily

activities for children to improve bilateral hand use. Table 4 provides the goals per family.

Table 4

COPM Goals

Family	Goal	COPM - Goal	Activity Category
1	1	Eating using both hands	Mealtime
	2	Putting on Top with both hands	Dressing
	3	Building Block Tower with both hands	Play
2	1	Assist with Dressing using both hands	Dressing
	2	Using both hands during mealtime	Mealtime
	3	Completing coloring using both hands	School work
3	1	Cutting food using both hands during mealtime	Mealtime
	2	Putting on socks independently	Dressing
	3	Throwing/Catching Ball with 2 hands	Play/sports

Table 4

Data from the pre-post intervention COPM reveals a significant positive change in performance and satisfaction for the goals for all families. All families demonstrated significant positive changes in perceived performance and satisfaction across all 3 goals.

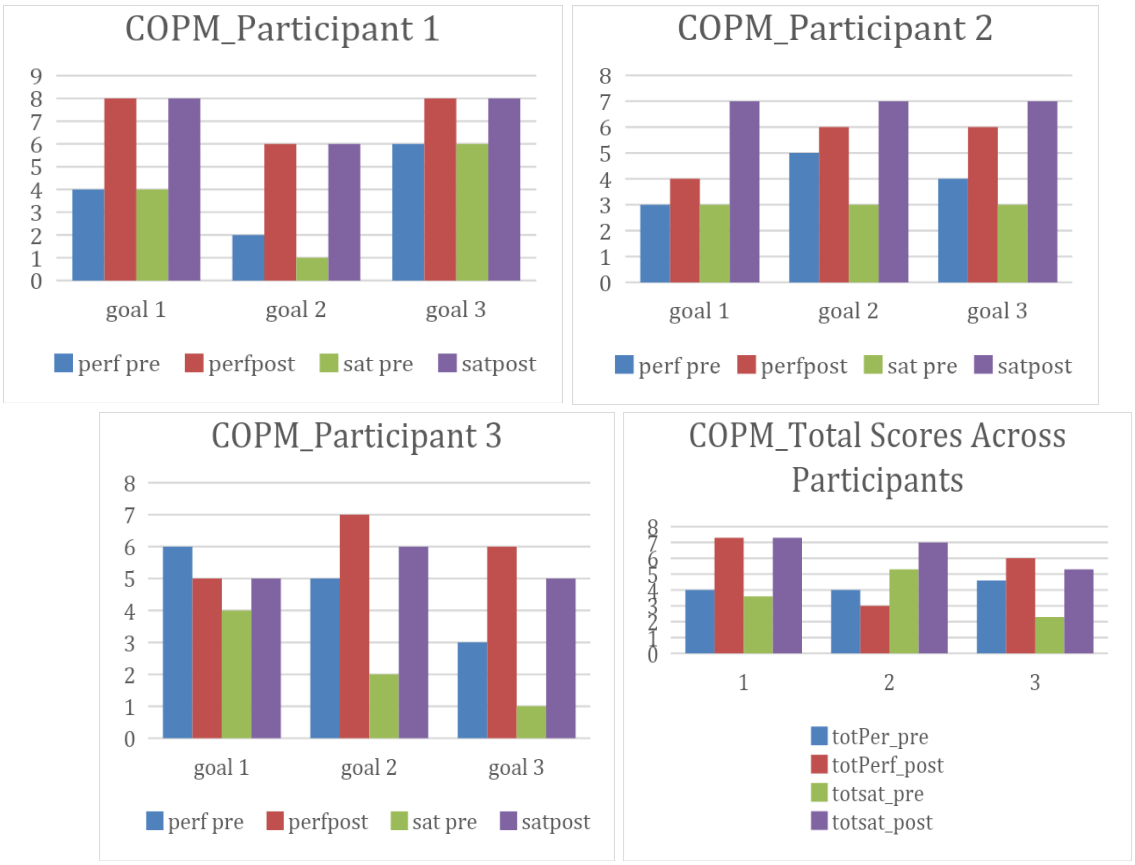

Figure 3: Pre- Post Intervention Performance and Satisfaction scores (Per Participant and Overall)

(Perf pre=performance prior to the intervention; Perfpost= performance after the intervention; Satpre= Satisfaction prior to intervention; SatPost= Satisfaction after the intervention; Prefix tot= scores aggregated across 3 goals for each of the participants.)

Families were able to use a variety of activities to practice bimanual skills. Table 5 presents the categories of activities and the time each family spent in each of these categories while practicing.

Table 5

Activities by Practice Blocks

Activity Category	Family 1	Family 2	Family 3
Mealtime	5-18 minutes	15-50 minutes	16-60 minutes
Free Play	1-30 minutes	10-30 minutes	15-45 minutes
Dressing	3-5 minutes	0-2 minutes	7-10 minutes
Bathing	17-20 minutes	10-20 minutes	8-15 minutes
Extracurricular Activities	5-75 minutes	10-30 minutes	20-30 minutes

Table 5

Some activities led themselves more naturally to practice of bimanual skills and the preference varied from family to family and depended on each family's routines (see Figure 4).

Total Time Spent with Each Activity by Category

	Family 1	**Family 2**	**Family 3**
Mealtime	124 mins	525 mins	135 mins
Free Play	154 mins	150 mins	370 mins
Dressing	55 mins	4 mins	58 mins
Bathing	152 mins	45 mins	38 mins
Extracurricular Activities	230 Mins	40 mins	80 mins

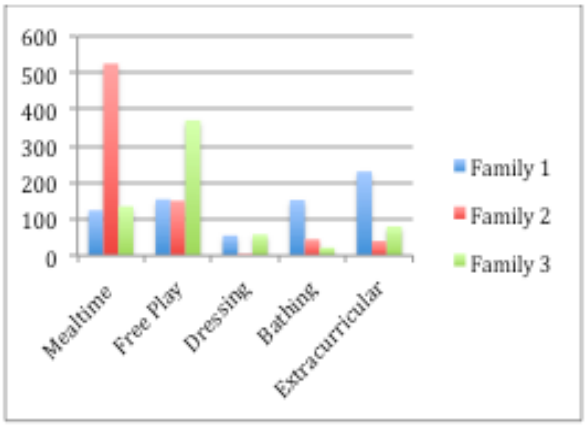

Figure 4 Total Time Spent in Each Activity Category

Qualitative data from the daily logs and satisfaction survey reveals that all 3 families were capable of embedding FAAM strategies into their daily routines.

Caregivers in Family's 1 & 2 reported that incorporation of strategies into their daily routines created a greater sense of accountability and practice convenience. Family 3 had difficulty with strategy incorporation at times as the majority of the child's daily activities were performed outside of the home. For all three families, there were days where life events impeded the caregiver's ability to implement FAAM strategies (i.e., a child emergency, family outings). While caregivers were not able to practice strategies on these days, some families suggested that they would "make up" practice time by practicing strategies on a day of the week that they would normally take off (ex., practicing strategies on Saturday to make up for a Thursday that they may have missed). Caregivers also reported a spontaneous attempt to carryover bimanual strategies to other daily activities without prompting, which may be a positive indication of increased body awareness, child acceptance and confidence with success during bimanual activity performance.

The interventionist was often met with difficulty in supporting the caregiver with maintaining the attention and motivation of the child during FAAM activities. This included motivation to complete task in full or use the new task approach and grading full use of the FAAM approach to prevent shut down or unwillingness to participate from the child. Future FAAM studies should incorporate a system for navigating through child behavioral challenges, receptiveness, as well as a decision tree for practitioners to know when to make a decision about employing these approaches. Another challenge included development of a negative view towards the presence of the interventionist, as the interventionist became associated with them needing to practice using both their hands. Future FAAM studies should incorporate a reward system for participation during

coaching sessions, this way the presence of the practitioner is viewed as an incentive as opposed to a burden to daily activity and routine engagement. Examples may be engagement in a desirable activity or game of choice prior to and after the coaching session.

Overall caregiver feedback regarding their experience with the FAAM was positive. Even within a short amount of time, participants reported satisfaction with FAAM and with their child's new attempts to incorporate both hands into daily activities. Caregiver responses from the FAAM Final Caregiver Survey regarding child included "we saw improvement in our child in such a short span of practice," and "my child does not have to be prompted as much to use his weaker side."

Pilot goal 2.

The second goal of the pilot was to examine the feasibility of the supports provided by the FAAM to enhance family engagement with the program and adherence as well as fidelity of the home program. Families were able to carry out a significant amount of practice per day. For Family 1 the average practice was *M=75min (35-115min-* child was sick one of the days); for Family 2 the average practice was *M=89.55min (60-107min);* for Family 3 *M=89.55min (15-95min- one day was 15 due to religious observation restrictions in activities).* Families have not missed a day in their logs. The FAAM Daily Activity Logs were used consistently by each family daily. All three families were able to log the activities independently by the end of each day, some however appeared to have difficulty tracking the form throughout the day as they were involved with other activities and/or siblings at times. Families suggested that daily logs need to be simplified with goals and activities pre-filled to reduce the time it took for

caregivers to report. Daily logs were deemed as necessary, because they were an effective formal point of communication between the caregiver and the interventionist for strategy modification. Using the responses at the end of the log form, the interventionist was able to identify if the caregiver was having difficulty with FAAM implementation, review the activities that were used that day, and contact the caregiver for further support.

Families reported difficulties with following consistent practice blocks (practice with an activity for at least 15 minutes or more). The caregivers in the study reported instances where practice lasted less than 15 minutes. However, they added more repetitions or other similar activities on their logs as they wanted to make sure that they reached the target of 90 minutes of practice. The interventionist also offered feedback and strategies to the families to encourage them to expand practice efforts during daily activities that would normally occur within shorter periods of time. (ex. Expanding practice during bath time by allowing the child to attempt to wash face with washcloth using 2 hands or incorporating a bath time game as opposed to completing the entire sequence for the child). During the pilot families reported that engagement in events outside the home, such as doctor's visits, religious observations, prevented them from reaching their daily goal. The interventionist and caregivers were able to discuss ways to incorporate practice using alternative activities during these days or make up the day/time lost.

The FAAM Caregiver Activity Questionnaire and Final Caregiver Questionnaire revealed the weekly caregiver views on self-confidence with home program execution and overall program acceptability at the end of the study. Each caregiver reported that they either maintained or increased confidence with FAAM strategy use in regards to:

consistency, modifying daily routines, adapting the home environment, decreasing frustration during bimanual task avoidance, rewarding the child and self for small progress, receiving support from others in the home, and commitment to making strategies part of their daily life. The final questionnaire revealed that all three families felt the approach was both caregiver and child friendly, and that the approach was *"manageable for the caregiver yet not overwhelming for the child,"* easy to share with other members of the family, motivating for the child to use both hands in other activities. All three families also reported that the FAAM provided adequate family support, with *"plenty of instruction and feedback," "fast and clear responses,"* and *"encouragement and motivation by study leader."*

Discussion.

This study aimed to test the feasibility of the service delivery strategies developed for the FAAM in supporting caregivers and children with a home program that follows effective principles of family-centered practice and evidence-based intensive motor learning protocols to increase bimanual hand use in children with HCP. HABIT in particular has been included in the FAAM as it is an intensive motor learning protocol that has shown effectiveness in improving bimanual hand use in children across numerous lab-based and camp-based studies (Gordon 2007; Brandao et al 2012; Brandao et al 2014; Sakzewski et al 2014) and presents a replicable design for practice that is child-motivated, encourages functional practice, and is least restrictive or invasive. The findings from this feasibility study demonstrate that the coaching aspects of the FAAM present a guideline approach that is acceptable with families, maintain program fidelity and support lifestyle modification that is essential to the development of bimanual

functional goals. Families started reporting changes in the way they carried out daily activities that supported their children's skill development and bimanual hand use. Families were able to carry out the 90 minute protocol most of the days within the two weeks, but unexpected changes in the routine (such as child sickness) or religious and cultural routines can prevent the implementation of the 90 hour regimes. Collaboration with the families can help develop more specific plans for these days and perhaps a "make up" day can help to maintain the practice intensity. Families also reported the need to consolidate the daily logs and activity feedback. The two forms have been merged for the main study into the FAAM daily activity logs. In the pilot study, the length of the intervention was limited and does not allow for changes in skilled motor behavior. Thus, measuring motor skills before and after the pilot intervention was not carried out.

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FEASIBILITY OF THE FAMILY ACTIVITY ADAPTATION MODEL (FAAM) IN IMPROVING BIMANUAL HAND USE IN CHILDREN WITH HEMIPLEGIC CEREBRAL PALSY

FAAM MANUAL

What is the FAAM?

The FAAM is a service delivery model used to support practitioners in developing a family-centered approach to learning and practicing skills. The approach pairs the family's everyday activities and routines with intensive motor training protocols to maximize family (child and caregiver engagement) in the process of learning new motor skills. A train-the-trainer approach is used in the format of a virtual home program to guide caregivers through understanding BIT strategies, and introducing, changing, and shaping motor strategies with the child in a natural, playful manner throughout their day. The "FAAM Process Model" is used to guide practitioners in developing a personalized home program that aids the caregiver and child with development of new daily habits that support bimanual functioning. The FAAM "family" is identified as the child and the primary caregiver supporting the child through the selected activities in their natural environment. The FAAM is specifically designed at this point, for children between the ages of 3 to 7, within MACS levels I, II and III. The FAAM is based on the framework and literature of the International Classification of Functioning, Disability and Health, Child and Youth Version (ICF-CY) and OT, and further supported through evidence-based protocols within motor learning and adult learning literature. The FAAM Process Model is defined by three primary procedures: Family Orientation, Activity Analysis and Adaptation, and Model Motor Intervention.

1. **Family Orientation:**

The family orientation process supports the practitioner with understanding the goals of the child and family, orienting to the family's daily activities and routines, and identifying the child's likes and interests. The information gathered during the family orientation is used to build rapport with the family and create an occupational profile. Occupations are life activities that are considered meaningful to the individual (American Occupational Therapy Association [AOTA], 2014).

a. The practitioner collaborates with the caregiver and child to better understand the lifestyle and preferences of the family. This is referred to as the environmental and personal factors that impact activity and routine performance during the study. Personal factors considered with the FAAM include current habits, behavioral patterns, coping strategies, and practice experiences (WHO, 2007) in relation to bimanual tasks. The environmental factors are reviewed on an individual level (WHO, 2007) and focus on the materials in the home that may be available for bimanual practice, the set-up of rooms in the home, and the people who may be able to support with practice strategies. The caregiver provides a detailed account of the child's daily schedule and items that the child prefers during mealtime, playtime, and dressing. Emphasis is placed on the materials that are of interest to the child for increased motivation and provide a sense of autonomy during activity selection (Wulf & Lewthwaithe, 2016).

Creating an Activity Profile for the Family. To create the family activity profile we need to ask questions and record the family's narrative and actual schedules. This facilitates the process of developing a comprehensive understanding on how the intervention can fit in the family's schedule and how the caregivers will be able to set reasonable goals and expectations about the program.

- What are the family activities in a typical week? (Time tables, habits and routines)
    - What the family routines during a typical day?
        - Sleep awake cycle
        - Eating/meal habits (i.e., social, time frames, etc.)
        - Family time
        - Schedules/activities that overlap and those that do not
        - Parent work schedules
        - Childcare and caregiving needs
        - Supports and challenges
        - Cultural values, beliefs, aspirations that are evident in the schedule
    - What are the family routines on the weekends? (mark the changes between the two routines). Repeat the questions above. Also consider additional components below.
        - Spiritual/religious routines

- Leisure activities
- Social activities
- Family time

b. Developing goals about the child. Goal development is guided by the COPM (Law et al., 1990) and focuses on self-care activities or participation in self-care routines where restrictions may be experienced due to limitations in bimanual functioning. The ICF-CY (2007) is used to guide the definitions of activity limitation and participation restriction for the FAAM. Activity limitation is defined as challenges that may be experienced by the child in executing (World Health Organization [WHO], 2007) bimanual tasks. Participation restriction is defined by difficulties the child may experience with completing (WHO, 2007) a bimanual self-care routine. The selected goal is categorized according to the most relevant occupational subdomain (AOTA, 2014). Occupational subdomains for children include ADLs, instrumental activities of daily living (IADLs), education, play, or social participation. ADLs are daily activities that target self-care and may involve bathing, toileting, dressing, and feeding. IADLs in the context of the FAAM are more complex activities that support life in the home, such as pet care and religious and spiritual activities. The education and play subdomains focus on learning activities and activities, respectively, that are enjoyable for the child.

Setting goals is a collaborative process that is client-centered, reasonable, and supports the child's functionality and self-efficacy. The specific areas of focus for the FAAM include mealtime, playtime, and dressing activities and routines that are most important to both the child and the caregiver and support independence and self-efficacy.

Mealtime Routines: Include the process of preparing, setting up for a meal and eating a meal. Observe how do parents and children carry out mealtime routines.

Consider with the caregivers the following:

- What is missing?
- What would make this process easier?
- What would be their expectation for the child in these routines?
- Where it is important for them to start? Prioritize the goal that is closer to the child's current abilities and what will make the child feel more accomplished.

Consider the role of the different contexts where the activity is conducted is very important: physical contexts (i.e., eating at the table, or eating at the couch, or eating while sitting on the floor, etc.), social context (i.e., eating alone, with others, etc.)

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Consider the role of the objects used, utensils, containers, packages.

Consider the child's motor ability and the support and challenges these contexts and objects are presenting.

Consider the time and timing of these activities.

Dressing/Undressing Routines: This includes the process of selecting, caring, preparing and putting away the garments, as well as, putting on and taking of clothes, use of fasteners.

Consider with the caregivers the following:

- What is missing?

- What would make this process easier?
- What would be their expectation for the child in these routines?
- Where it is important for them to start? Prioritize the goal that is closer to the child's current abilities and what will make the child feel more accomplished.

Consider the role of the different contexts where the activity is conducted is very important: physical contexts (i.e., dressing while sitting at a chair, or on a high bed or while sitting on the floor, etc.), social context (i.e., dressing alone, with help of others, etc.)

Consider the role of the objects used, garment pieces, sizes, fastener complexity.

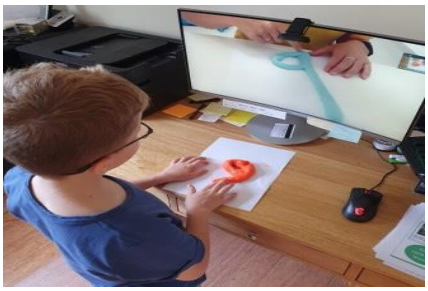
Consider the child's motor ability and the support and challenges these contexts and objects are presenting.

Consider the time and timing of these activities.

Playtime routines: Include a variety of gross and fine motor play, alone and with partners. Consider with the caregivers the following:

- What is missing?
- What would make this process easier?
- What would be their expectation for the child in these routines?
- Where it is important for them to start? Prioritize the goal that is closer to the child's current abilities and what will make the child feel more accomplished.

Consider the role of the different contexts where the activity is conducted is very important: physical contexts (i.e., play indoors or outdoors, playing standing vs. sitting on chair or on the floor, etc.), social context (i.e., playing alone, with siblings, with peers, with adults etc.)



Consider the role of the objects used, equipment, pieces, sizes, complexity of toys and games.

Consider the child's motor ability and the support and challenges these contexts and objects are presenting.

Consider the time and timing of these activities.

2. Activity Analysis:

The activity analysis is completed to provide the practitioner with a scope of how the child's personal and environmental factors may impact their ability to execute bimanual activities or participate in bimanual household routines. The specific personal factors taken into consideration for each bimanual goal are the family values, beliefs, and spirituality connected to the activity or routine, upper limb motor performance skills, and cognitive demands needed to support task completion (AOTA, 2014). Environmental factors are determined by assessing specific personal, physical, cultural, social, temporal, and virtual contexts that may support or challenge task performance (AOTA, 2014).

The sequencing and timing of the task is then modified based on natural observation of the child performing each task and the goals for hand use.

The FAAM Activity Analysis Form summarizes this process for each goal:

Goal/Activity Description:_____

1.Occupation:
Check the line that best describes the area of occupation for the activity:

_____Activity of Daily Living
_____Instrumental Activity of Daily Living
_____Education
_____Work
_____Play
_____Leisure
_____Social Participation

2. Values, beliefs, spirituality associated with activity participation:

3. Contexts: Indicate how each supports or challenges the child's participation in the bimanual task:

Context	Supports	Challenges
Physical/Space Demands		
Social		
Cultural		
Personal		
Temporal		
Virtual		

3. Objects Required for Task:

4. Social demands of Activity:

5. Task Sequence and Timing:

7. Analysis of muscle movements required:
Please check the primary muscle movements the child will need to complete the task

Muscle	Minimal Use	Great Use
Shoulder Flexion		
Shoulder Extension		
Shoulder Abduction		
Shoulder Adduction		
Shoulder Internal Rotation		
Shoulder External Rotation		
Elbow Flexion		
Elbow Extension		
Wrist Supination		
Wrist Pronation		
Wrist Flexion		
Wrist Extension		
Thumb Flexion		
Thumb Adduction		
Finger Flexion		
Finger Extension		
Trunk Flexion		
Trunk Extension		
Trunk Rotation		
Lower Extremities		

Activity Adaptation

The activity adaptation process supports the process of guiding the child and caregiver through activity practice and performance. To encourage motivation and attention while using the affected hand, the FAAM promotes engagement in normal daily activities, tasks that are identified as meaningful to the child and family, and social comparative feedback (Wulf & Lewthwaite, 2016). The specific FAAM strategies used to support motor learning in the social context

include: increasing control over bimanual task conditions, providing choices for bimanual tasks, negotiating the structure of tasks, providing practice conditions that encourage task success and emphasize successful performance, and directing the individual's attention to the task goal vs. use of both hands. Creating opportunities where learning is empowering for the child and guided by their goals and interests is imperative. Providing social support and feedback further enhances the process of learning. Social comparative feedback emphasizes the use of positive feedback (regardless of actual results) that suggests individual performance is more effective, or greater than normal or average, to enhance motor learning (Lewthwaite & Wulf, 2010). The FAAM protocol utilizes a real context-specific need that children and families identify and trains families to provide the comparative feedback support while the child engages in functional tasks.

Strategies for engaging the child in the activity:

- Encourage Autonomy
  - Allow the child to control motor task conditions:
    - Allow child to select task and be active in problem solving
  - Provide options that lead to a choice
    - Provide 3-4 choices that are a part of child's interest or goals
  - Use instructional language & Incidental Choices
    - Letting the child choose the extent of practice or the spacing of practice
    - Allowing choice of activity order

        - Autonomy supportive vs. controlling guidance during the activity
            - Allow child to choose sequence of task steps and order of overall task completion during supervisory visit
            - Negotiate with child to come up with select bimanual activity/task rules
- Supporting Expectations
    - Practice conditions that enhance learners' performance expectancies
        - Introduce bimanual activities to the child that provide graded challenge and produce earlier successes (Backward Chaining Tasks)
            - Practitioner presents 75% of task completed, leaving last 25% of task for child to complete
            - Practitioner presents 50% of task completed, leaving 50% of task for child to complete
            - Practitioner presents 25% of task completed, leaving 75% of task for child to complete
            - Child completes 100% of task with therapist supervision and positive affect
        - Feedback that emphasizes successful performance, while focusing less on unsuccessful attempts
            - Give positive reinforcement of praise to successfully performed aspects of tasks

- Avoid providing hand over hand assistance. If needed you can change the environment or the task to make it easier so that you can help the child be more independent when working with the task.

- Motor performance enhanced by suggesting to performers that they are likely to do well under pressure
  - Create a playful, competitive/goal oriented game atmosphere for completing tasks
- Positive Affect
  - Use a positive affect towards coaching task completion

- Attentional Factors
  - External Focus of Attention
    - Instructions directing attention away from one's body parts or self and to the intended movement effect
- Self-Efficacy/Frustration
    - Instruct the child in reaching task goal without reference to use of both hands
    - Encourage use of both hands through age-appropriate and playful activity goals
    - Encourage exploration, curiosity, spontaneity in task
    - Activity is motivating and fun
    - Encourage problem Solving: Practitioner uses cognitive strategies to help child work through achieving parts of task

- Alternative Strategies
- Asking For Help
- Trying Again

Environmental Factors that can improve participation

- Focus on factors that change the environment (to accommodate the needs) not the child
- Create opportunities for practicing movements that can be used across different activities.
- The time and timing of the activities is important to allow for experimentation, exploration, and trial and error problem-solving in the activity.

4. Model Motor Intervention _The role of HABIT protocol

The HABIT is an evidence-based bimanual therapy training protocol. It creates opportunities for children and youth with hemiplegia to increase bimanual functioning through intensive practice (60-90 hours) that does not restrain the affected hand and uses child-friendly bimanual activities. The specific principles used in the FAAM focus on: practice intensity, whole-task practice, part-task practice, task grading, and functional goal training. Practice intensity has been found to be a key ingredient in promoting neuroplasticity (Gordon et al., 2007; Friel et al., 2016) and is promoted through provision of a consistent daily practice schedule for families, meeting a 60-hour minimum throughout the course of the program. Whole-task practice (practice of the

task in a sequential and successive manner continuously for at least 15-20 minutes) is the primary focus for motor practice in the FAAM protocol, while part-task practice (practicing components of motor skills in smaller segments of time with increasing complexity and repetition) is encouraged as a secondary focus (ex. during task set-up or clean-up time). The FAAM approach to the HABIT application is used in an effort to remain consistent with the family's normal routine and modify activity approaches in a manner that allows for lifestyle adaptation within the family's timing.

Skill Progression. Skill progression for the FAAM refers to the process of helping the child challenge themselves with using alternative strategies when carrying out a task, carrying out the task in different environments, help them find ways to adapt the task or the environment as needed for being successful.

Increasing the task difficulty is a key element of the skill progression. From the HABIT protocol the recommendation is to increase the task difficulty the level when the child has successfully carried out the activity in 3 out of 5 times (Gordon, 2004). For example, after 5 times of preparing a meal, if the child is able to chop 2, 5, 6, 7, and 8 pieces of a banana the level of difficulty is changed. Other ways to change the difficulty include changing the speed, accuracy, or the materials used. In the FAAM protocol we model these changes for the child and we encourage the child to become more aware of how to challenge themselves. We also coach the parents on how to carry out this process. We focus on the achievements and encourage the caregiver and the child

to identify the successful strategies and use them across tasks (Adaptive Decision Making Framework- Dimitropoulou, 2019).

Model Motor intervention for the caregiver. The motor intervention process of the FAAM includes use of coaching strategies to model intensive-motor techniques for the caregiver and child. The coaching strategies are guided by adult learning principles of engagement and evidence-based methods for coaching parents in the use of therapeutic strategies (Kaiser & Roberts, 2013). The coaching strategies are defined by three steps: Teach, Coach, and Review. These processes allow the practitioner to share specific modifications necessary for successful task performance with the family. The specific strategies are defined as:

Teach—introduction of bimanual motor strategies to be learned

Following the principles described above we train the parents in the FAAM process. Training starts with the initial session using their child's videos as the reference point. During the initial training parents are encouraged to break down the activities and see their child's abilities and areas that need improvement. This training is essential to form the goals and help parents think of these goals in the context of their family's lifestyle. Teaching continues throughout the intervention process in the supervision process as parents bring back videos, questions, challenges and successful stories to discuss with the therapists.

Tools like monitoring strategies used are important for developing a family-based profile of what works (see the form below):

Weekly Form for monitoring strategies

	Motor Difficulty	Things that can help
Mealtime		
Playtime		
Dressing		

Strategy Chart

Materials:

Mealtime –

Playtime -

Dressing -

Coach—illustration of bimanual motor strategies taught, supporting child and caregiver engagement, monitoring progress)

The therapist provides coaching through encouraging parents to gain more autonomy, adjust their expectations and learn how to monitor and encourage their children's progress. Therapists also model for parents activity modifications, teaching the child new strategies, strategies to engage the child in a challenging task, ways to expand learned strategies in new activities and contexts, through direct treatment sessions that the parents observe and actively participate.

Review (activity logging, providing new strategies for task success). Creating logs and videos is key to the success of the program. It provides opportunities for reflection, development of questions, understanding of the needs and the challenges and monitoring progression of the skills. It also ensures that adequate

practice time is allocated to support expectations for skill progress (see Activity Log form)

Appendix C

FAAM Activity Analysis Form

Use the following form to analyze how the child performs bimanual activities
Participant ID #:_____

1. Goal/Activity
   Description:_____

1. Occupation:

Check the line that best describes the area of occupation for the activity:
_____Activity of Daily Living
_____Instrumental Activity of Daily Living
_____Education
_____Work
_____Play
_____Leisure
_____Social Participation

2. Values, beliefs, spirituality associated with activity participation:

3. Contexts: Indicate how each supports or challenges the child's participation in the bimanual task:

Context	Supports	Challenges
Physical/Space Demands		
Social		
Cultural		
Personal		
Temporal		
Virtual		

4. Objects Required for Task:

5. Social Demands of Activity:

6. Task Sequence and Timing:

1._____
2._____
3._____
4._____
5._____
6._____
7._____
8._____
9._____
10._____

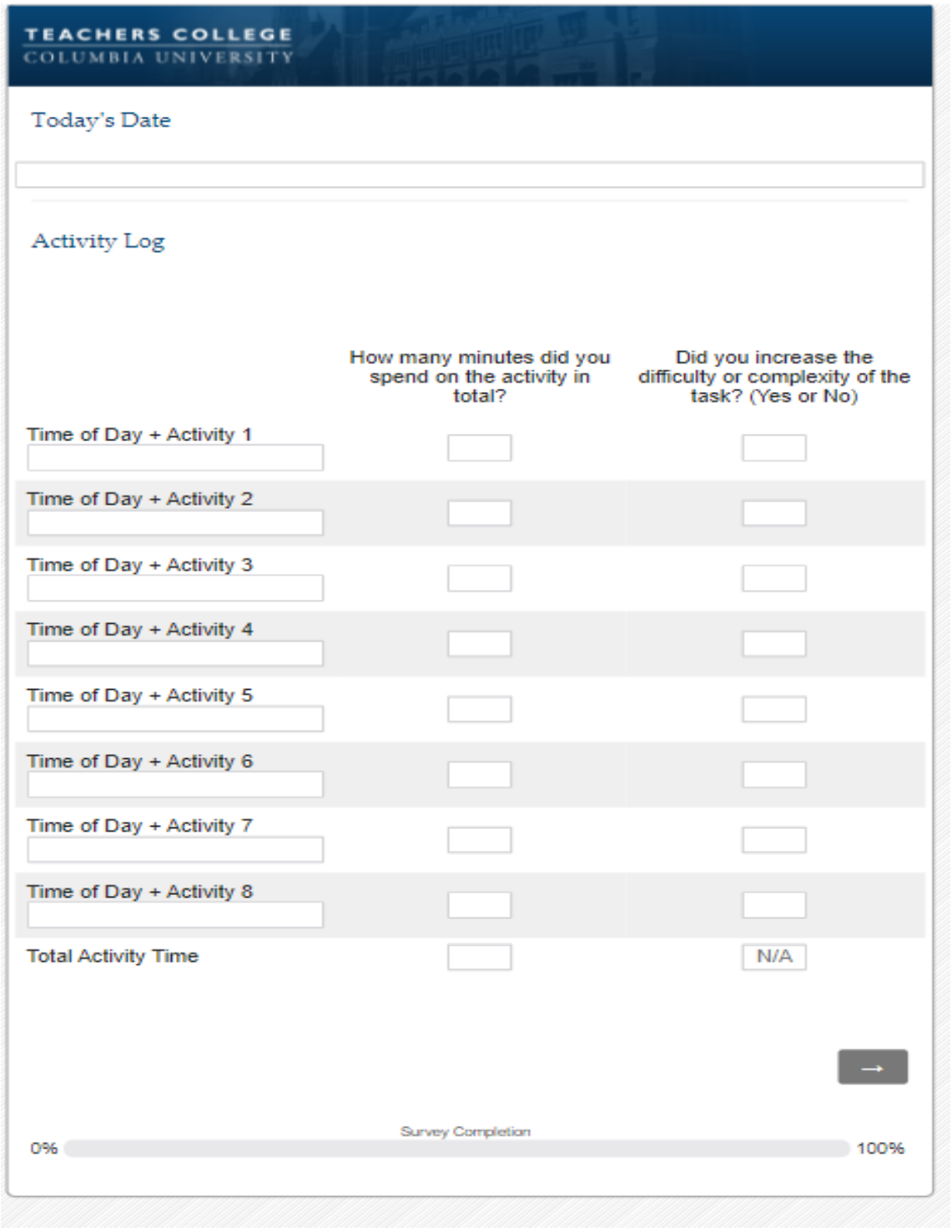
7. Analysis of muscle movements required:
Please check the primary muscle movements the child will need to complete the task

Muscle	**Minimal Use**	**Great Use**
Shoulder Flexion		
Shoulder Extension		
Shoulder Abduction		
Shoulder Adduction		
Shoulder Internal Rotation		
Shoulder External Rotation		
Elbow Flexion		
Elbow Extension		
Wrist Supination		
Wrist Pronation		
Wrist Flexion		
Wrist Extension		
Thumb Flexion		
Thumb Adduction		
Finger Flexion		
Finger Extension		
Trunk Flexion		
Trunk Extension		
Trunk Rotation		
Lower Extremities		

Adapted from: Thomas, H (2012). *Occupation-Based Activity Analysis*. Thorofare, NJ: SLACK, Incorporated

Appendix D

FAAM Daily Activity Log



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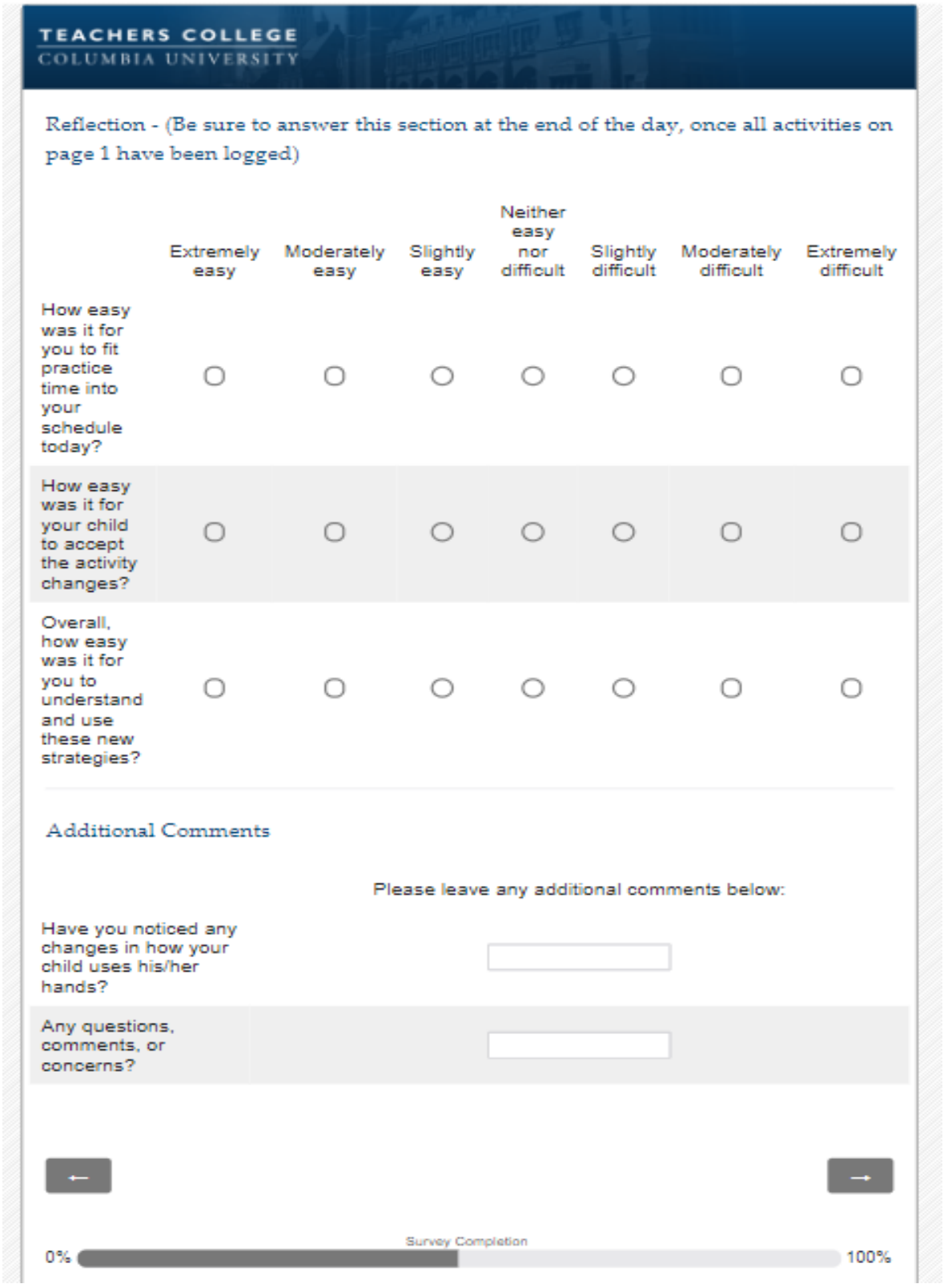
Today's Date

Activity Log

	How many minutes did you spend on the activity in total?	Did you increase the difficulty or complexity of the task? (Yes or No)
Time of Day + Activity 1		
Time of Day + Activity 2		
Time of Day + Activity 3		
Time of Day + Activity 4		
Time of Day + Activity 5		
Time of Day + Activity 6		
Time of Day + Activity 7		
Time of Day + Activity 8		
Total Activity Time		N/A

→

Survey Completion
0% 100%



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Reflection - (Be sure to answer this section at the end of the day, once all activities on page 1 have been logged)

	Extremely easy	Moderately easy	Slightly easy	Neither easy nor difficult	Slightly difficult	Moderately difficult	Extremely difficult
How easy was it for you to fit practice time into your schedule today?	○	○	○	○	○	○	○
How easy was it for your child to accept the activity changes?	○	○	○	○	○	○	○
Overall, how easy was it for you to understand and use these new strategies?	○	○	○	○	○	○	○

Additional Comments

Please leave any additional comments below:

Have you noticed any changes in how your child uses his/her hands?	
Any questions, comments, or concerns?	

←

→

Survey Completion

0% 100%

Appendix E

Canadian Occupational Performance Measure

CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

Authors:
Mary Law, Sue Baptiste, Anne Carswell,
Mary Ann McColl, Helene Polatajko, Nancy Pollock

The Canadian Occupational Performance Measure (COPM) is an individualized measure designed for use by occupational therapists to detect self-perceived change in occupational performance problems over time.

Client Name:		
Age:	Gender:	ID#:
Respondent (if not client):		
Date of Assessment:	Planned Date of Reassessment:	Date of Reassessment:

Therapist:
Facility/Agency:
Program:

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Printed in Canada

STEP 1: IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES

To identify occupational performance problems, concerns and issues, interview the client, asking about daily activities in self-care, productivity and leisure. Ask clients to identify daily activities which they want to do, need to do or are expected to do by encouraging them to think about a typical day. Then ask the client to identify which of these activities are difficult for them to do now to their satisfaction. Record these activity problems in Steps 1A, 1B, or 1C.

STEP 2: RATING IMPORTANCE

Using the scoring card provided, ask the client to rate, on a scale of 1 to 10, the importance of each activity. Place the ratings in the corresponding boxes in Steps 1A, 1B, or 1C.

STEP 1A: Self-care

IMPORTANCE

Personal Care
(e.g., dressing, bathing, feeding, hygiene)

_____ ☐
_____ ☐
_____ ☐

Functional Mobility
(e.g., transfers, indoor, outdoor)

_____ ☐
_____ ☐
_____ ☐

Community Management
(e.g., transportation, shopping, finances)

_____ ☐
_____ ☐
_____ ☐

STEP 1B: Productivity

Paid/Unpaid Work
(e.g., finding/keeping a job, volunteering)

_____ ☐
_____ ☐
_____ ☐

Household Management
(e.g., cleaning, laundry, cooking)

_____ ☐
_____ ☐
_____ ☐

Play/School
(e.g., play skills, homework)

_____ ☐
_____ ☐
_____ ☐

STEP 1C: Leisure

IMPORTANCE

Quiet Recreation
(e.g., hobbies, crafts, reading) _____ ☐
_____ ☐
_____ ☐

Active Recreation
(e.g., sports, outings, travel) _____ ☐
_____ ☐
_____ ☐

Socialization
(e.g., visiting, phone calls, parties, correspondence) _____ ☐
_____ ☐
_____ ☐

STEPS 3 & 4: SCORING - INITIAL ASSESSMENT and REASSESSMENT

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems. At reassessment, the client scores each problem again for performance and satisfaction. Calculate the new scores and the change score.

Initial Assessment:			**Reassessment:**	
OCCUPATIONAL PERFORMANCE PROBLEMS:	PERFORMANCE 1	SATISFACTION 1	PERFORMANCE 2	SATISFACTION 2
1. _____	☐	☐	☐	☐
2. _____	☐	☐	☐	☐
3. _____	☐	☐	☐	☐
4. _____	☐	☐	☐	☐
5. _____	☐	☐	☐	☐
SCORING:	PERFORMANCE SCORE 1	SATISFACTION SCORE 1	PERFORMANCE SCORE 2	SATISFACTION SCORE 2
Total score = Total performance or satisfaction scores / # of problems	/ = ☐	/ = ☐	/ = ☐	/ = ☐

CHANGE IN PERFORMANCE = Performance Score 2 ☐ – Performance Score 1 ☐ = ☐

CHANGE IN SATISFACTION = Satisfaction Score 2 ☐ – Satisfaction Score 1 ☐ = ☐

ADDITIONAL NOTES AND BACKGROUND INFORMATION

Initial Assessment:

Reassessment:

Appendix F

FAAM Virtual Home Program Study—Mini-CHEQ

FAAM Virtual Home Program Study

The Mini-CHEQ Evaluation

Please use the link below to complete the Mini CHEQ Evaluation:

https://www.cheq.se/miniquestionnaire

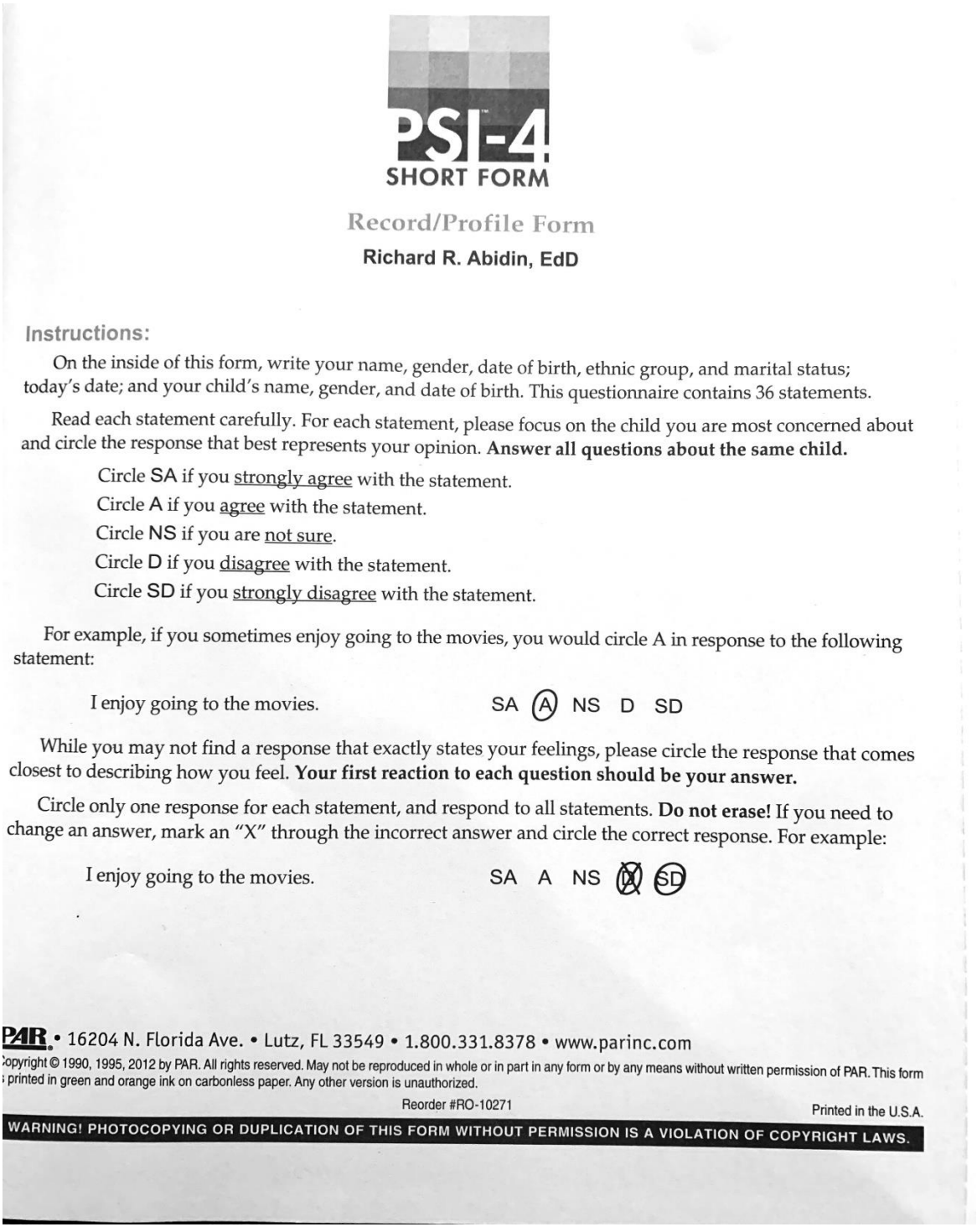
Once the test is complete, please download your results and add it to your folder. If you need assistance please contact me at:

Eo2232@tc.columbia.edu

(973) 415-9405

Appendix G

Parenting Stress Index (PSI-4) Short Form



PSI-4
SHORT FORM

Record/Profile Form

Richard R. Abidin, EdD

Instructions:

On the inside of this form, write your name, gender, date of birth, ethnic group, and marital status; today's date; and your child's name, gender, and date of birth. This questionnaire contains 36 statements.

Read each statement carefully. For each statement, please focus on the child you are most concerned about and circle the response that best represents your opinion. **Answer all questions about the same child.**

Circle SA if you strongly agree with the statement.
Circle A if you agree with the statement.
Circle NS if you are not sure.
Circle D if you disagree with the statement.
Circle SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA (A) NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. **Your first reaction to each question should be your answer.**

Circle only one response for each statement, and respond to all statements. **Do not erase!** If you need to change an answer, mark an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS (X) (SD)

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PSI-4 SHORT FORM

Answer Sheet

Name _____ Gender _____ Date of birth ____/____/____

Ethnic group _____ Marital status _____ Today's date ____/____/____

Child's name _____ Child's gender _____ Child's date of birth ____/____/____

SA = Strongly Agree **A = Agree** **NS = Not Sure** **D = Disagree** **SD = Strongly Disagree**

1. I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2. I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3. I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4. Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5. Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6. I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7. There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8. Having a child has caused more problems than I expected in my relationship with my spouse/parenting partner.	SA	A	NS	D	SD
9. I feel alone and without friends.	SA	A	NS	D	SD
10. When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11. I am not as interested in people as I used to be.	SA	A	NS	D	SD
12. I don't enjoy things as I used to.	SA	A	NS	D	SD
13. My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14. When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
15. My child smiles at me much less than I expected.	SA	A	NS	D	SD
16. Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
17. My child is very emotional and gets upset easily.	SA	A	NS	D	SD
18. My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19. My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20. My child is not able to do as much as I expected.	SA	A	NS	D	SD
21. It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD
22. I feel that I am: (Choose a response from the choices below.)	1	2	3	4	5

1. a very good parent.
2. a better-than-average parent.
3. an average parent.
4. a person who has some trouble being a parent.
5. not very good at being a parent.

23. I expected to have closer and warmer feelings for my child than I do, and this bothers me.	SA	A	NS	D	SD
24. Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD

SA = Strongly Agree **A** = Agree **NS** = Not Sure **D** = Disagree **SD** = Strongly Disagree

25.	My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26.	My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27.	I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
28.	Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.	SA	A	NS	D	SD
29.	My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30.	When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
31.	My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD
32.	I have found that getting my child to do something or stop doing something is: (Choose a response from the choices below.)	1	2	3	4	5

1. much harder than I expected.
2. somewhat harder than I expected.
3. about as hard as I expected.
4. somewhat easier than I expected.
5. much easier than I expected.

33.	Think carefully and count the number of things which your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. (Choose a response from the choices below.)	1	2	3	4	5

1. 1-3
2. 4-5
3. 6-7
4. 8-9
5. 10+

34.	There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35.	My child's behavior is more of a problem than I expected.	SA	A	NS	D	SD
36.	My child makes more demands on me than most children.	SA	A	NS	D	SD

Please do not write in this area.

Appendix H

Ease of Caregiving for Children Measure

Ease of Caregiving for Children

Description: The Ease of Caregiving for Children is a parent-completed measure of how difficult it is for them to safely help their children participate in activities of daily living.

Instructions for Parents:

Please think about HOW DIFFICULT it is for YOU to SAFELY HELP YOUR CHILD to do activities of daily living.
When thinking about how difficult it is for you, please consider the following things:

- Safety
- Physical demands on you
- Your confidence about providing the help
- The time needed to complete the activity

You have 5 choices for answering the questions on the next page:

5. **No help is needed –** Your child does the activity of daily living without the help of an adult.
4. **No difficulty –** You help your child and you have no difficulty providing help.
3. **A Little difficulty** – You help your child and you have only a little difficulty providing help.
2. **Somewhat difficult** – You help your child and providing help is somewhat difficult.
1. **Very difficult** – You help your child and providing help is very difficult.

CIRCLE THE ANSWER THAT DESCRIBES YOUR CHILD.

HOW DIFFICULT IS IT FOR YOU TO SAFELY HELP YOUR CHILD.....

Ease 1: to move at home and in the community?	5	4	3	2	1
Ease 2: to position for sleeping?	5	4	3	2	1
Ease 3: to position for feeding?	5	4	3	2	1

Ease 4: to position for bathing?		5	4	3	2	1
Ease 5: to position for playing?		5	4	3	2	1
Ease 6: to put on / take off clothing?		5	4	3	2	1
Ease 7: to put on / take off an orthosis or brace (if applicable)?	Not applicable	5	4	3	2	1
Ease 8: to bathe / clean and tidy?		5	4	3	2	1
Ease 9: to use the potty or toilet, or for you to change his/her diapers?		5	4	3	2	1
Ease 10: to eat?		5	4	3	2	1
Ease 11: to drink?		5	4	3	2	1
Ease 12: to get in and out of a car / van / bus?		5	4	3	2	1

Scoring Instructions and Conversion Table

Sum the raw scores on the 12 items and use the following chart to determine the scaled score.

Summed Raw Score	Scaled Score	Summed Raw Score	Scaled Score	Summed Raw Score	Scaled Score
60	100.0	43	51.5	26	34.5
59	89.6	42	50.2	25	33.5
58	83.2	41	49.0	24	32.5
57	79.0	40	47.9	23	31.4
56	75.7	39	46.8	22	30.3
55	73.0	38	45.8	21	29.2
54	70.5	37	44.8	20	27.9

53	68.2	36	43.8	19	26.6
52	66.1	35	42.8	18	25.0
51	64.1	34	41.9	17	23.4
50	62.3	33	40.9	16	21.3
49	60.5	32	40.0	15	18.8
48	58.7	31	39.1	14	15.4
47	57.1	30	38.2	13	9.7
46	55.6	29	37.3	12	0.0
45	54.1	28	36.4		
44	52.8	27	35.5		

Acknowledgements:

The development of this measure was funded by the Canadian Institutes of Health Research and the National Institute of Disability and Rehabilitation Research.

The authors acknowledge the contribution of Stephen M. Haley for his work as an author, in collaboration with Robert J. Palisano and Sarah Westcott McCoy, on the Pediatric Physical Therapy Outcomes Management System (PPT-OMS). The Ease of Caregiving for Children Measure had its genesis from items on the Early Movement Outcomes Program of the PPT-OMS.

Reference:

Ward, KD, Chiarello, LA, Bartlett, DJ, Palisano, RJ, McCoy SW, Avery, L. (2014). Ease of Caregiving for Children: A measure of parent perceptions of the physical demands of caregiving for young children with cerebral palsy. *Research in Developmental Disabilities.* 35(12), 3403-3415. (doi: 10.1016/j.ridd.2014.08.023).

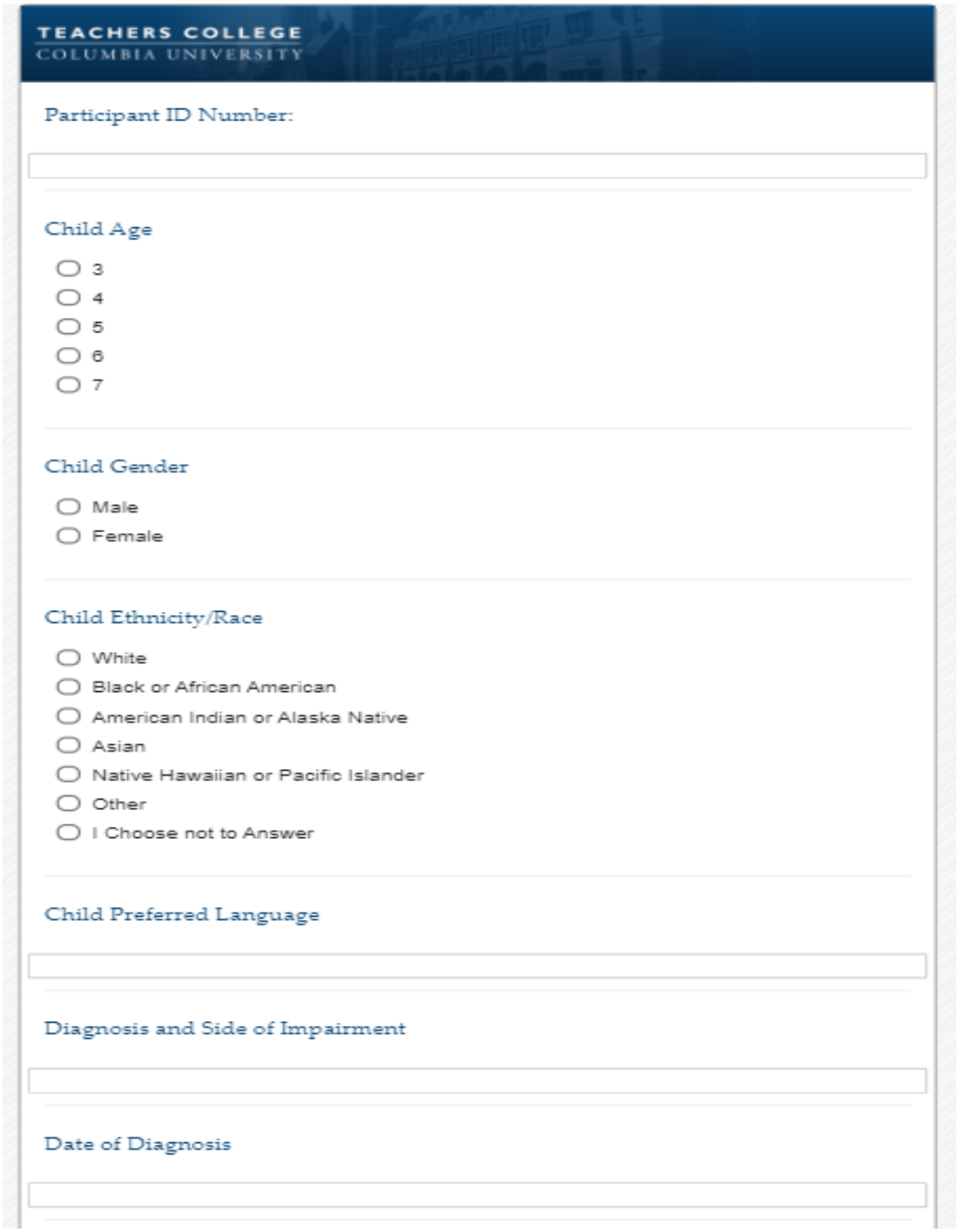
Appendix I

FAAM Caregiver Satisfaction Survey

Question:	Response:
1. **Was this approach easy for you to adapt to your daily routine?** • Please explain your experience.	
2. **About How much practice were you realistically able to accomplish daily using this new approach to your activIties? (Time estimate per day)**	
3. **Did you feel that** this approach was both caregiver- **and child- friendly?**	
4. **Are you satisfied with the support that this study provided for your family?**	
5. **Are you satisfied with the results you have seen with your child?**	
6. **Would you recommend this home program to a friend?**	

Appendix J

FAAM Demographic Survey



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Participant ID Number:

Child Age

- 3
- 4
- 5
- 6
- 7

Child Gender

- Male
- Female

Child Ethnicity/Race

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other
- I Choose not to Answer

Child Preferred Language

Diagnosis and Side of Impairment

Date of Diagnosis

Gestational History: Full Term?

- ○ Yes
- ○ No

Gestational History: Please specify any complications

Child's Birth Weight

NICU Stay? Please Specify (if applicable)

Developmental History: Please provide the approximate age of each milestone

Rolling	
Sitting	
Crawling	
Crusing	
Walking	
First Sounds	
First Words	

School: Type of School and Grade (please select all that apply)

- ☐ Public
- ☐ Private
- ☐ Other
- ☐ Pre-School
- ☐ Pre-K
- ☐ Kindergarten
- ☐ First Grade
- ☐ Second Grade
- ☐ Third Grade

Please list all therapies your child is currently receiving (during the period of this study, if any)

Parent 1: Age

Parent 1: Gender

- ◯ Male
- ◯ Female

Parent 1: Ethnicity/Race

- ◯ White
- ◯ Black or African American
- ◯ American Indian or Alaska Native
- ◯ Asian
- ◯ Native Hawaiian or Pacific Islander
- ◯ Other

Parent 1: Preferred Language

Parent 2: Ethnicity/Race

- ◯ White
- ◯ Black or African American
- ◯ American Indian or Alaska Native
- ◯ Asian
- ◯ Native Hawaiian or Pacific Islander
- ◯ Other
- ◯ I choose not to answer

Parent 2: Preferred Language

Marital Status

- ◯ Married
- ◯ Widowed
- ◯ Divorced
- ◯ Separated
- ◯ Never married
- ◯ I choose not to answer

Income

- ◯ Less than $10,000
- ◯ $10,000 - $29,999
- ◯ $30,000 - $49,999
- ◯ $50,000 - $69,999
- ◯ $70,000 - $89,999
- ◯ $90,000 - $110,000
- ◯ More than $110,000
- ◯ I choose not to answer

Parent 1 Education: Please indicate the highest level achieved

- ◯ Less than high school
- ◯ High school graduate
- ◯ Some college
- ◯ 2 year degree
- ◯ 4 year degree
- ◯ Professional degree
- ◯ Doctorate
- ◯ I choose not to answer

Parent 2 Education: Please indicate the highest level achieved

- ◯ Less than high school
- ◯ High school graduate
- ◯ Some college
- ◯ 2 year degree
- ◯ 4 year degree
- ◯ Professional degree
- ◯ Doctorate
- ◯ I choose not to answer

Appendix K

FAAM Video Recording Instructions

Video Recording Instructions:

- The video recordings are collected to give us an idea of how we can better help your child use his/her hands during common everyday activities and come up with a personalized therapy program.
- When recording, **please remember to complete the activity with your child as you normally would**. We would prefer to see them attempt to complete the task independently, however if you normally provide them with assistance this is ok

Materials Needed: Cell Phone Camera

1. Please record **three 5-minute videos** of your child when he/she is **eating a meal.**
2. Please record **three 5-minute videos** of your child **getting dressed** (ex. Putting on socks, pants, a jacket, a shirt)
3. Please record **three 5-minute videos** of your child when he/she is **playing with a toy/game/activity** that requires use of both hands
4. Each video should be **recorded on different days**
5. Make sure the camera is positioned in front of the child where both of his/her hands can be seen facing forward
6. At the end you will have a **total of 9 videos recorded**. Please upload all of the videos to your personal Google drive link.

Video Checklist:

	DAY 1	DAY 2	DAY 3
MEALTIME VIDEO	☐	☐	☐
PLAYTIME VIDEO	☐	☐	☐
DRESSING VIDEO	☐	☐	☐

If you require assistance or have any questions, feel free to contact me at:

Eo2232@tc.columbia.edu or (973) 415-9405

Appendix L

FAAM Weekly Strategy Form

ID:
Week:

Strategy Chart

	Motor Difficulty	Things that can help
Mealtime		
Playtime		
Dressing		

Materials:
Mealtime –

Playtime -

Dressing -